Working Plan

of the

Home and Community-Based Services and Consumer-Directed Care Commission

Introduction	
Activity 1	**Identify the current number of and current level of funding for home and community-based services and consumer-directed care programs for individuals with disabilities in the State of Missouri.**
Activity 2	**Develop a tool or mechanism for assessing the effectiveness of these services and programs in addressing the needs of individuals with disabilities.**
Activity 3	**Identify the number of individuals with disabilities in the State of Missouri that are institutionalized.**
Activity 4	**Identify the number of waiting lists for home and community-based services or consumer-directed care programs and evaluate the pace at which individuals move from these lists.**
Activity 5	**Examine whether existing programs and services provide individuals with disabilities who may be eligible for community-based treatment with information regarding this option.**
Activity 6 Activity 7	**Recommend any modifications or changes that may be needed to improve existing home & community-based services and consumer-directed care programs;** **Recommend any potential means of expanding home & community-based services or consumer-directed are programs.**
Activity 8	**Develop a process for transitioning individuals with disabilities who are institutionalized and who are eligible for community-based treatment into community-based treatment settings.**

DRAFT

December 8, 2000

Activity No. 1: Identify the current number of and current level of funding for home and community-based services and consumer-directed care programs for individuals with disabilities in the State of Missouri.

Background Information

This first activity was designed to identify the current number of and current level of funding for home and community-based services and consumer-directed care programs for individuals with disabilities in Missouri.

Each state department (or program division) had its own listing of the current number and current level of funding for home and community-based services and consumer-directed care programs for individuals with disabilities in Missouri. This section will describe these numbers separately by appropriate state program.

Department of Elementary and Secondary Education • Division of Vocational Rehabilitation

Personal Assistance Services (PAS) Programs

The Division of Vocational Rehabilitation operates three Consumer-Directed Personal Assistance Services (CD-PAS) Programs for the benefit of consumers who require personal care services. The three programs are Non-Medicaid Eligible, Medicaid State Plan and Independent Living Waiver. These statewide programs are administered locally by twenty-one Centers for Independent Living.

The Non-Medicaid Eligible (NME) Program has been in existence since 1985. This program enables consumers with physical disabilities who are “employed or ready for employment” to maintain or seek such employment by utilizing personal care services through this program. The NME Program is funded through state general revenue appropriation. This program served as the model for the development of the Medicaid State Plan (MSP) and the Independent Living Waiver (ILW) Programs.

The Medicaid State Plan (MSP) Program has been in existence since 1993. This program targets the Medicaid-eligible population with physical disabilities. Eligible consumers may access personal care services up to a monthly maximum of $2,295. The MSP Program is funded through a combination of Federal and State funds.

The Independent Living Waiver (ILW) Program started January 1, 2000. This program targets the Medicaid-eligible population with physical disabilities or cognitive disabilities who require Personal Care services above

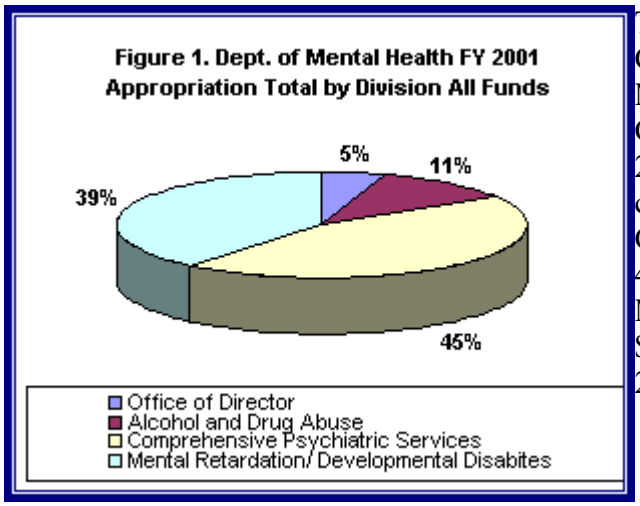
the MSP maximum of $2,295 or Specialized Medical Equipment and Supplies or Environmental Accessibility Adaptations or Case Management. (See Table 1.)

Table 1. Number of Consumers and Level of Funding – Division of Vocational Rehabilitation

	NME Program	MSP Program	IL Waiver Program
Number of Consumers	189	623	470
Average Hours Per Day	5.7	5.1	3.8
Appropriations:			
State Fiscal Year 2000	$5,012,648	$7,245,880	(Included in MSP
State Fiscal Year 2001	$5,012,648	$10,751,771*	Appropriations)
FY 2000 CD-PAS consumers to exit			
Nursing homes	33		

Note: Data as of 10/31/00
*Does not include HB1111 Funding

Department of Mental Health



The Department of Mental Health consists of four divisions: Comprehensive Psychiatric Services, Alcohol and Drug Abuse, Mental Retardation and Development Disabilities and the Office of the Director. The total operating budget for the FY 2001 is $682,823,496. Of this amount $630 million represents core funding and $52.8 million is appropriated as new funding. Comprehensive Psychiatric Services received approximately 45% of the budget (or $310,922,739) and the Division of Mental Retardation/Develop-mental Disabilities 39% (or $266,344,377). Figure 1 presents the operating budget for FY 2001.

Department of Mental Health • Division of Alcohol and Drug Abuse

The Division of Alcohol and Drug Abuse offers prevention and treatment services through a network of community contracted providers. The only services that take place in Department of Mental Health inpatient facilities are 96-hour involuntary commitments. The Division routinely monitors the community-based providers and their treatment staff, who must meet state certification standards. A methodology for priority distribution of new resources, based on both population and risk factor measures, has recently been developed.

The Division's total budget for FY 2001 is $77,017,172. Of the budgeted amount, funding for treatment services is 74.3 percent; prevention 14.7 percent; Substance Abuse Traffic Offender Program 4.6 percent; compulsive gambling 0.6 percent; and administration 5.9 percent. (See Table 2.)

Table 2. Funding Distribution by Service: ADA

Funding Distribution by Service		% of Total
Administration	$4,535,884	5.9
Prevention & Education	$11,329,766	14.7
Treatment	$57,193,891	74.3
SATOP	$3,505,255	4.6

Compulsive Gambling	$452,486	0.6
	$77,017,172	

The sources of funding were predominantly federal (48.1%) and general revenue (40.9%). (See Table 3.)

Table 3. Sources of Funding: ADA

Sources of Funding		% of Funding
General Revenue	$31,486,222	40.9
Mental Health Earnings	$1,872,255	2.4
Compulsive Gambling	$452,486	0.6
Health Initiative Fund	$6,178,385	8.0
Federal	$37,027,824	48.1
	$77,017,172	

Approximately 68.2% of Missouri residents served by the Division of Alcohol and Drug Abuse were served by the outpatient rehabilitation program. (See Table 4.)

Table 4. Number of Consumers Served: ADA

Type of Service	Number of Consumers Served	% of Funding
Detoxification	4,206	10.0%
Residential Rehabilitation	9,187	21.8%
Outpatient Rehabilitation	28,685	68.2%
	42,078	

Department of Mental Health • Comprehensive Psychiatric Services

The Division of Comprehensive Psychiatric Services (CPS) is charged with the delivery of services to persons with mental illness throughout the State of Missouri.

The Division divides Missouri into 25 service areas. Each service area has a contracted Community Mental Health Center designated as the division's administrative agent. These administrative agents serve as the primary entry and exit point for state mental health services and are responsible for the assessment and services to persons in their assigned areas and for providing follow-up services for persons released from state-operated inpatient services. Children and youth are provided services in much the same way through contracts with administrative agents and state-operated children's hospitals.

Supported community living programs are provided for persons with mental illness who do not have a place to live or who need more structured services while in the community. These programs range from nursing homes to apartments and other standard living accommodations in the community. Persons in these programs receive support through case management and community psychiatric rehabilitation programs provided by administrative agents and affiliated providers.

Approximately 75.7% of the consumers served by Comprehensive Psychiatric Services (38,269) were served by the general outpatient category. An additional 22.9% of the consumers (11,570) were served by the Community Psychiatric Rehabilitation program (both adults and children). An additional 745 consumers were served in the Families First program (1.5%). (See Table 5.)

Table 5. Non-Institution Community Support: Comprehensive Psychiatric Services

Service	**Number** ***(as of June 1, 2000)***
	11,570*

Community Psychiatric Rehabilitation (adults and children)	
Families First (children)	745*
Other Outpatient (adults and children)	38,269*

*Numbers duplicated between programs.

The age distributions can be found on Table 6. Most of those served (94.3%) were between 18 and 64 years of age.

Table 6. Non-Institutional Community-Based Residential Settings

	Comprehensive Psychiatric Services	
Age	**Supported Community Living** *(Independent Apartment, Supported Living, Natural Home, etc.)* *(as of June 1, 2000)*	
Under 18	49	3.7
18-64	1241	94.3
65 and over	26	2.0
Total	**1316**	

A further analysis by the type of community living arrangement found that the majority of those in supportive community living arrangements resided in Residential Care Facilities (77.5%). Table 7 presents these findings.

Table 7. Supportive Community Living Arrangements (as of June 1, 2000)

	Comprehensive Psychiatric Services				
Age	**Nursing Home**	**Residential Care Facility**	**Residential Treatment**	**Group Home**	**Supported Living**
Under 18	1	1	76	6	49
18-64	209	2016	3	59	1241
65 and over	306	254	0	0	26
Total	**516**	**2271**	**79**	**65**	**1316**
	12.1%	53.5%	1.9%	1.5%	31.0%

The *Program Review* for the Department of Mental Health listed the proposed funding for specific Comprehensive Psychiatric Services community-based programs for FY 01. Table 8 lists these proposed expenditures by program. The major expenditures are projected for the Adult Community Supports program ($80,709,750 or 38.7%) and the Community Psychiatric Rehabilitation Program ($59,100,000 or 28.3%).

Table 8: Expenditures by Program FY'01 Projections:

	Comprehensive Psychiatric Services			
Program	**General Revenue**	**Federal**	**Other**	**Total Proposed Expenditure**
Adult Community Supports	$71,917,007	$8,472,040	$320,703	$80,709,750
Crisis Services	$169,750	$6,430,545	.	$6,591,295
Community Psychiatric Rehabilitation Program	$23,075,000	$36,025,000		$59,100,000
Adult Community Residential Services	$12,913,415			$12,913,415
Forensic Services	$1,246,105			$1,246,105
Program for Homeless	$906,392	$4,326,302		$5,232,694
Medications and Medication Related Services	$6,832,973			$6,832,973
Nursing Home Reform	$56,000	$168,000		$224,000
Civil Detention Legal Fees	$1,100,000			$1,100,000

Youth Community Support	$20,559,482	$4,845,902	$600,000	$26,005,384
Youth Residential Services	$4,243,059			$4,243,059
Division of Family Services/Divisio of Youth Services			$1,330,907	$1,330,907

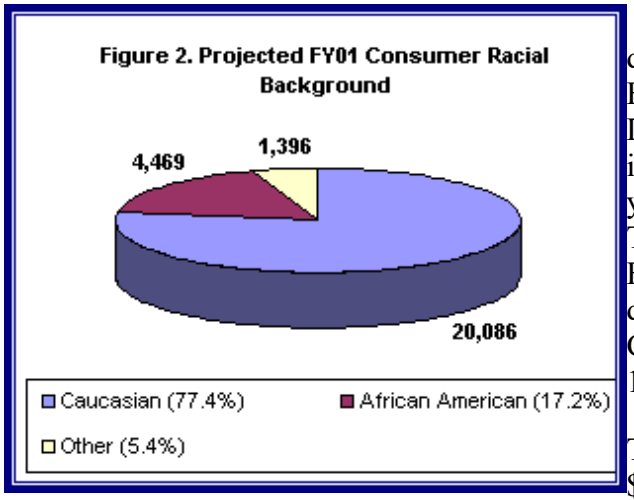
Department of Mental Health • Division of Mental Retardation/ Developmental Disabilities

The Division of Mental Retardation and Developmental Disabilities (MRDD) has the responsibility of insuring that mental retardation and developmental disabilities prevention, evaluation, care, habilitation, and rehabilitation services are accessible, wherever possible. The Division serves persons who have been diagnosed with mental retardation or some other developmental disability. A qualifying individual's mental retardation must have occurred before the age of 18, while any other developmental disability must have occurred before age 22. All conditions must be expected to continue indefinitely and result in substantial functional limitations. The Division's primary mission is to help improve the lives of persons with developmental disabilities through programs and services which enable those persons to live independently and productively, given their individual needs and capabilities.

The Division is moving forward in its expansion of consumer and family directed supports. This will allow individuals with developmental disabilities to receive supports in *the* most integrated setting – with their families or in their own homes, take a leading role in planning and directing their services and supports, and participate fully in all aspects of home, school, work, and community life.

The Division operates habilitation centers and regional centers that provide or purchase specialized services. Eleven regional centers form the framework for the system, backed by six habilitation centers, which provide residential care and habilitation services for persons with more severe disabilities.

The regional centers, based in eleven principal sites and supported by numerous satellite locations, are the primary points of entry into the system. The regional centers provide assessment and case management services, which include coordination of each consumer's person-centered plan. Each center serves from three to fifteen counties.

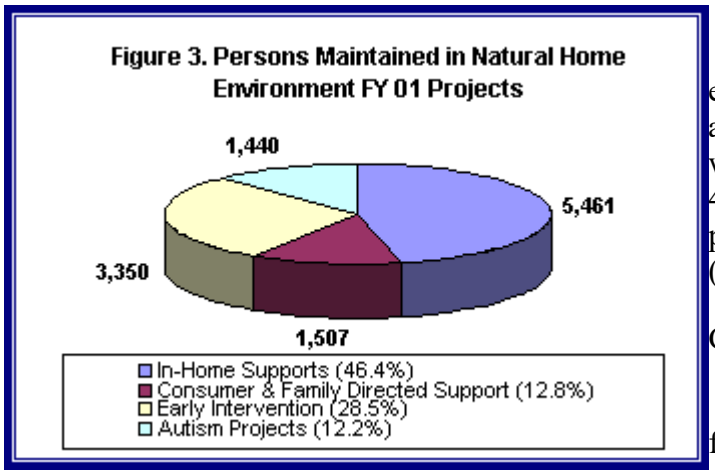


A total of 25,951 individuals with mental retardation or developmental disabilities are projected to be served during FY'2001 by the Division of Mental Retardation/Developmental Disabilities by Regional Centers. Almost half of these individuals (46.6% or 12,091) will be under the age of 21 years. The remainder (13,860) are 21 years of age or older. The majority of those served are male (15,327 or 59.1%). Females represent 40.9% of those served (10,624). The racial distributions show that the majority (77.4% or 20,086) are Caucasians. There were 4,469 (17.2%) African Americans and 1,396 (5.4%) "other" category. See Figure 2.

The appropriations for these community programs is $123,040,928. The majority of the funding is found in the Community Residential Program ($68,534,872 = 55.7%). An additional 16.4% of the funds are designated for the Consumer & Family Directed Support Program ($20,147,071). See Table 9.

Table 9. Community Programs Appropriation: Division of Mental Retardation/Developmental Disabilities

Type of Program	Funding	Percent
Community Residential, (General Revenue)	$68,534,872	55.7
Federal, Personal Assistant, Organized Healthcare Delivery System	1,200,000	1.0
Community Residential, (General Revenue Federal)	4,544,329	3.7
Welfare Reform – (General Revenue)	224,900	0.2
Consumer & Family Directed Support Program	20,147,071	16.4
Inter-agency Payment Fund (Div. Family Services)	1,049,857	0.9
Senate Bill 40 funds, Mental Health Trust Fund	5,852,732	4.8
Autism – (General Revenue)	3,714,965	3.0
Early Intervention – (General Revenue)	1,282,007	1.0
Early Intervention – (Federal)	3,763,919	3.1
Early Intervention, Mental Health Interagency	4,547,312	3.7
Subtotal community programs	114,861,964	-
Community Support Staff – (Federal)	8,179,464	6.6
Total	**$123,040,928**	**100.0**



For persons maintained in their natural home environment, the FY 2001 budget projects that an additional 11,758 persons will be served. Most of these will be in the in-home support program (5,461 or 46.4%). Approximately 28.5% of the consumers were projected to be served in the Early Intervention Program (1,440 children). See Figure 3.

Consumer Counts are duplicated between categories

The appropriations for these programs can be found on Table 10. The in-home support program represented 34.1% of the total ($11,398,840). The early intervention program is 28.7% of the budget ($9,593,238).

Table 10. Appropriations

Program		Funding	Percent
In-Home Supports		$11,398,840	34.1%
Consumer & Family Directed Support		8,748,231	26.1%
Autism Projects		3,714,965	11.1%
Early Intervention		9,593,238	28.7%
	Total	33,455,274	

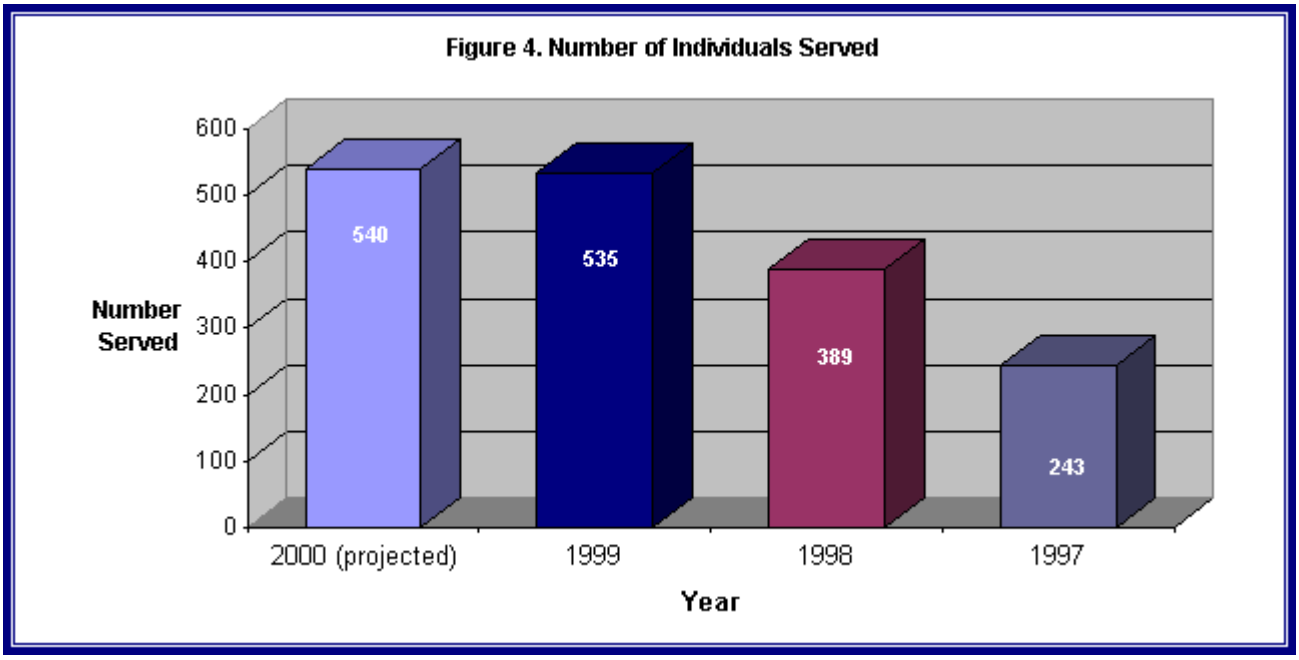
Department of Health • Bureau of Special Health Care Needs
Adult Head Injury Program

In the Adult Head Injury Program, service coordination is available statewide, free of charge, to survivors of traumatic brain injury who have reached their 21st birthday, regardless of financial status. Individuals may contact a service coordinator, or may be referred, with their permission, by physicians, family, friends, rehabilitation centers, service agencies, and support organizations.

Rehabilitation services listed below are available to individuals who are eligible for the program, whose income is 185% of Federal Poverty Guidelines or lower. These services may be provided to eligible clients when necessary to facilitate the client's achievement of a long term goal as indicated in the Program Service Plan. The provision of rehabilitation services is subject to availability of funds which are appropriated annually. All rehabilitation services must be prior authorized. The Department of Health is payer of last resort. The Head Injury Program Service Coordinator will assist the client to apply for any other payment resources before submitting requests for use of program funds.

- Neuropsychological Evaluation and Consultation
- Behavioral Assessment and Consultation
- Adjustment Counseling
- Comprehensive Day Program
- Transitional Home and Community Support
- Pre-Vocational/Pre-Employment Training
- Supported Employment/Follow Along
- Special Instruction
- Physical Therapy Evaluation/Treatment
- Occupational Therapy Evaluation/Treatment
- Speech Therapy Evaluation/Treatment
- Recreation Activities
- Respite Care
- Transportation

The number of individuals served during the past few years has increased from 243 in 1997 to 535 in 1999 and a projected 540 in 2000. (See Figure 4.)



Some of the demographics about those served are found on Table 11. Approximately 80% of those served are Caucasian.

Table 11. Racial and Ethnic Background – Adult Head Injury Program

Race	White	Black	Hispanic	American Native	Asian	Other	Totals
FY2000 (projected)	421	110	6	0	3	0	540
FY1999	417	109	6	0	3	0	535
FY1998	304	81	3	0	1	0	389
FY1997	187	55	0	0	1	0	243

Most program participants were under 40 years of age (over 70%). Table 12 presents these age breakdowns.

Table 12. Age Distribution: Adult Head Injury Program

Age	20-29	30-39	40-49	Totals
FY2000 (projected)	209	185	146	540
FY1999	207	183	145	535
FY1998	85	170	134	389
FY1997	68	94	81	243

The majority of those served were males (72.5%) . (See Table 13.)

Table 13. Gender: Adult Head Injury Program

Gender	Male	Female	Totals
FY2000 (projected)	392	148	540
FY1999	388	147	535
FY1998	279	110	389
FY1997	198	45	243

Proposed budget or appropriations has also increased over the past few years. (See Table 14.)

Table 14. Fiscal Appropriations: Adult Head Injury Program

Fiscal Year	Appropriation or Budget
FY1997	$1,009,503
FY1998	$1,009,503
FY1999	$1,182,993
FY2000 (Projected)	$1,232,993

Expenditures for the Adult Head Injury Program for FY 1999 and FY1998 are listed on Table 15. In 1999 approximately 25% of the expenditures were in the category of transportation (25.4%), In-home supports (24.6%) and facility-based day activity (24.8%).

Table 15. Expenditures – 1998-1999

Service	FY 1998		FY 1999	
Supported Employment	$34,329.72	5.2	$75,121.94	6.8
Functional Living (facility-based)	$125,905.00	19.0	$125,598.00	11.4
Physical, Occupational and Speech	$3,979.50	0.6	$3,171.00	0.3
Transportation	$116,931.00	17.6	$280,056.26	25.4
In-Home Support	$221,705.00	33.4	$271,380.00	24.6
Day Activity (facility-based)	$116,193.50	17.5	$274,305.80	24.8
Day Program (facility-based)	$0.00		$12,960.00	1.2
Personal Care	$1,884.75	0.3	$0.00	
Community Support	$18,155.50	2.7	$34,712.85	3.1
Counseling	$19,611.50	3.0	$25,248.20	2.3
Recreation	$4,836.00	0.7	$1,690.00	0.2

Department of Social Services • Division of Aging

The mission of the division of Aging is to promote, maintain, improve, and protect the quality of life and quality of care for Missouri's older adults and persons with disabilities so they may live as independently as possible with dignity and respect. The Missouri Division of Aging, Missouri Care Options program provides services both in community and long-term settings for those who are Medicaid eligible or potentially eligible and in need of assistance. The types of in-home services include:

- Help with activities of daily living such as grooming, bathing, dressing, eating;
- Help with complex physical needs;
- A companion to relieve family caregivers, giving them time to run errands or attend to personal needs
- Help with housekeeping, laundry, meal preparation, shopping and other services
- In-home nursing care;
- Supervised adult day care programs; and
- Well-prepared, nutritious meals delivered to the home through arrangements with the Area Agencies on Aging.

The Division of Aging spent a total of $84,385,268 on home and community-based services in 1999.

Table 16 presents findings that reflect the number of individuals served by the Department of Social Services, Division of Aging programs.

Table 17 presents the Medicaid Services most likely impacted by the Olmstead decision.

Table 16. Significant Data Tables

Significant Data	FY1998	FY1999	FY2000
Number of enrolled In-home Provider Agencies	255	333	390
Average Monthly Number of In-Home Services Clients'			
Personal Care	3,197	3,422	3,183
Advanced Personal Care	171	222	233
Nurse	445	616	681
Homemaker Care	5,021	4,605	3,863
Hourly Respite	338	355	309
Advanced Respite (Hourly, 6-8 Hour Block and 24 Hour Block)	120	97	109
Nurse Respite	26	66	38
Adult Day Health Care	73	35	87
Counseling	79	82	89
Clinical Consultation	N/A	N/A	N/A
Annual Number of In-Home Services Clients			
Accessing SSBG/GR funds	7,807	7,569	8,781
Accessing a combination of Medicaid and SSBG/GR funds	44,588	46,526	53,021
Annual Expenditures by Service			
Personal Care	$6,391,979	$6,817,737	$7,206,235
Advanced Personal Care	$588,794	$706,534	$794,283
Nurse Visits	$381,980	$543,525	$613,507
Homemaker	$7,628,430	$7,086,034	$6,554,674
Hourly Respite	$1,095,936	$1,244,743	$1,191,334
Advanced Respite (Hourly, 6-8 Hour Block & 24 Hour Block)	$803,458	$678,167	$513,477
Nurse Respite	$264,206	$270,950	$196,587
Adult Day Health Care	$143,195	$97,267	$141,459
Counseling	$80,303	$69,761	$81,581.68
Clinical Consultation	N/A	$87,300	$87,300
Personal Care Attendant Pilot Project	$180,000	$173,536	$180,000
Unit Cost by Service Type			
Personal Care	$11.46	$11.94	$12.94
Advanced Personal Care	$15.50	$15.98	$16.98
Nurse Visits	$35.60	$36.08	$37.08
Homemaker Care	$11.46	$11.94	$12.94
Hourly Respite	$9.60	$10.08	$11.08
Advanced Respite (Hourly Block)	$12.60	$13.06	$14.08
Advanced Respite (6-8 Hour Block)	N/A	$75.00	$76.00
Advanced Respite (24 Hour Block)	N/A	$175.00	$176.00
Nurse Respite	$75.00	$75.00	$76.00
Adult Day Health Care	$41.50	$42.70	$43.70
Counseling	$26.08	$26.08	$27.08
Clinical Consultation	N/A	N/A	N/A

Table 17. Programs Most Likely Impacted by Olmstead Decision

	Program	Core Appropriations	Medicaid Clients Served	Waiting List	Age Group	Footnotes/Further Explanations
Home and Community Based Waiver Programs	Aged and Disabled Waiver	(See Footnote 1.) Total HCB State GR Total HCB Federal Plus Home Delivered Meals Federal	20,745	0	63 and older	Footnote 1: Part of Home and Community Based Services (HCB) Appropriation (HB 1111 Section 11.445)
	Aids Waiver	(See Footnote 1.) Total HCB State GR Total HCB Federal	74	0	No age requirement	
	(Footnote 2.) Independent Living Waiver	DESE-DVR State GR	200	0	18-64	Footnote 2: See Dept. of Elementary and Secondary Education Division of Vocational Rehabilitation response.
	(Footnote 3.) MOCDD (Lopez Waiver)	DMH State GR	143	9	birth through 18	Footnote 3: See Department of Mental Health response.
	(Footnote 4.) MR/DD Waiver	DMH State GR	7,625	0	No age requirement	Footnote 4: Mental Retardation and/or Developmental Disabilities Waiver (see Department of Mental Health response).
	Physical Disabilities Waiver	(Footnote 5.) Total HCB State GR Total HCB Federal	11	0	21 and over	Footnote 5: Part of Home and Community Based Services (HCB) Appropriation (HB 1111 Section 11.445)
	Adult Day Health Care	(Footnote 5.) Total HCB State GR Total HCB Federal	807	0	18 and over	
Home and Community Based State Plan Services	Home Health Services	(Footnote 5.) Total HCB State GR Total HCB Federal	5,997	0	Under 21* 21 and over **	Footnote 5: Part of Home and Community Based Services (HCB) Appropriation (HB 1111 Section 11.445) *must be medically necessary **must meet home bound requirement
	(Footnote 6.) Personal Care Services	(Footnote 7.) Total HCB State GR Total HCB Federal Total DESE-DVR	Home - 28,773 RCF I&II -7,917 DMH – 140 DVR-150	0	Under 21* 21 and over**	Footnote 6: See Dept. of Elementary and Secondary Education Division of Vocational Rehabilitation (DESE-DVR) response. Footnote 7: 2 sources for State GR: Part of Home and Community Based Services (HCB) Appropriation (HB 1111 Section 11.445) and DESE-DVR

						*must be medically necessary **must assess at nursing home level of care
Medicaid State Plan Rehabilitation Services	Durable Medical Equipment (Footnote 10.) Community Psychiatric Rehabilitation (CPR) (Footnote 11.) Comprehensive Substance Treatment & Rehabilitation (C-STAR) (Footnote 12.) Comprehensive Day Rehabilitation (Footnote 13.) First Steps Program (Footnote 13.) School Based Services – Part B	(Footnote 9.) Total Rehab State GR Total Rehab Federal DMH State GR DESE DESE	15,014 6,126 1,505 24 Information not available Information not available	0 0 0 0	No age requirement No age requirement No age requirement No age requirement birth to 3 3 to 5* K-12**	Footnote 9: Part of the Rehabilitation and Specialty Service Appropriation. Footnote 10: See Department of Mental Health response. Footnote 11: See Department of Mental Health response. Footnote 12: See Department of Mental Health response. *Program Restrictions:* One year program participation. Footnote 13: DESE funded program. *if age 5 after August 1 = DESE **if age 5 before August 1 = school district.
Medicaid State Plan Targeted Case Management Services	(Footnote 14.) Targeted Case Management for Chronically Mentally Ill (CMI) Adults (Footnote 15.) Targeted Case Management for Severely Emotionally Disturbed (SED) Children (Footnote 16.) Targeted Case Management for Mental Retardation and/or Developmental Disabilities (MRDD)	DMH State GR DMH State GR DMH State GR	15,086	0 0 0	16 or older 0 through 20 No age restriction	Footnote 14: See Department of Mental Health response. Footnote 15: See Department of Mental Health response. Footnote 16: See Department of Mental Health Response. *Program Restrictions:* Developmental disabilities must be manifested before age 22 to receive this service.

The Department of Social Services Division of Medical Services provides a variety of home and community-based programs. The following tables show the Medicaid expenditures and numbers of persons served by:

- Missouri Medicaid State Plan Rehabilitation Services (Table 18);
- Missouri State Plan Targeted Case Management (Table 19);
- Missouri Medicaid Home and Community-Based 1915C Waiver Programs (Table 20); and
- Missouri Medicaid State Plan Programs (Table 21).

Activity No. 2: Develop a tool or mechanism for assessing the effectiveness of these services and programs in addressing the needs of individuals with disabilities.

Background Information

One charge of the Commission was to develop a mechanism for assessing the effectiveness of these services and programs in addressing the needs of individuals with disabilities. In order to complete this, the activities that have been conducted by state agencies to date were identified. A survey was conducted with the participating state agencies concerning their current outcome measurements and what types of activities they would propose to assure that these services and programs were in fact addressing the needs of individuals with disabilities.

Summary of Related Public Comments

Some comments were received during public hearings and commission meetings about the need to evaluate any changes that are based on the Olmstead Commission. Dr. James Caccamo, Chair of the Mental Health Commission, led this charge.

I think a final challenge facing you all, is to develop an evaluation plan that will help the commission determine if your recommendations are having a positive effect and positive outcomes for our clients who choose community-based living and community-based services. Mental Health Commission strongly urges that you think about evaluation now as we are building an effective system that people with disabilities will have choice in their service provider and in their place of residence. Now is the time to think of evaluation, not after the recommendations are put in place. Evaluation must not be an afterthought but rather an intentional process that informs you.

He recommended that the evaluation plan be formative so as *we move along over the years, what the evaluation system learns can help inform and change we're not building a system that's firm and cast in concrete.* (Commission Hearing 11/13/00)

Some participants in the Public Hearings expressed their views on quality assurance and evaluation.

If the state develops more community services, the state should consider an accreditation and/or evaluation of these services. One speaker wanted a national system *I'm here also to urge the Commission to -- in designing community services to not support a state-operated accreditation system, but rather to look at a national accreditation system.* (Columbia).

Sometimes when people with disabilities remain in their own home, family members take advantage of them. *I've also seen people who are cared for by family members who took advantage of them and only wanted to keep them at home maybe for their Social Security check for some financial means. Our concern is is there going to be monitoring of those people who are going to be caregivers of people with disabilities.*

State Agency Information

The next pages present the findings from the state agencies. Two questions were asked in the state interviews: (1) What quality assurance activities are currently conducted by your agency; and (2) If you were developing a tool assessing effectiveness of services to and programs in addressing the needs of individuals with disabilities, what areas would be looked at (e.g. physical setting of placement, opportunity for inclusion in community, consumer-directed) and what process would you use to do this: a tool (i.e. instrument) or mechanism (process)?

In order to develop an effective measure, it needs to be well integrated into the current system of outcome measurement. Therefore, each agency also collected different outcome measures at the time of the survey.

Department of Elementary and Secondary Education • Division of Vocational Rehabilitation

The Department of Elementary and Secondary Education, Division of Vocational Rehabilitation utilizes different mechanisms to assure quality and appropriateness of care. These mechanisms include quality assurance, consumer satisfaction surveys, outcome studies, and agency profiles.

Quality Assurance Activities Currently Conducted

The following is a description of the quality assurance activities of the Personal Care program of the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. Several types of activities are currently used to measure the effectiveness of their services.

Consumer Satisfaction

When cases are closed by the Centers for Independent Living, a postcard is sent to the consumer. There are several questions on the postcard that measure overall consumer satisfaction with Independent Living Services. The data from the surveys are compiled on an annual basis by Statewide Independent Living Council.

Outcome Studies

All Centers for Independent Living complete a Federal RSA Section 704 Report which is compiled by the Division of Vocational Rehabilitation, Rehabilitation Services for the Blind and the Statewide Independent Living Council. The report contains data regarding goals met to determine the effectiveness of service provisions.

Quality Assurance

Vocational Rehabilitation conducts ongoing monitoring activities, such as case reviews, training and technical assistance, and home visits with CIL PAS participants. CILs contact consumers monthly, with face-to-face consumer contacts required on a quarterly basis for a minimum of 12 contact hours per year. There is an appeal process available to each PCA applicant/recipient who feels they were denied service or if they disagree with an agency decision.

How Agency Would Develop Assessment Tool

The Division of Vocational Rehabilitation has been working toward expanding these efforts. The Division has asked the Statewide Independent Living Council (SILC) to examine this issue and come up with recommendations. They would like to begin working on a continuous improvement model. Two recommendations the Division would like to work on first include:

1. Tailoring some of the consumer satisfaction survey questions to include specifics about personal care assistant or develop a separate survey process to measure this.

2. The Statewide Independent Living Council (SILC) has voted to recommend the Center for Management Assistance Outcome Based Training to be available to all CILs.

Department of Mental Health • Division of Alcohol and Drug Abuse

The Department of Mental Health, Division of Alcohol and Drug Abuse utilizes different mechanisms to assure quality and appropriateness of care. These mechanisms include quality assurance activities, consumer satisfaction surveys, ombudsman activity, outcome studies, appeal process, and agency profiles.

Quality Assurance Activities Currently Conducted

The Missouri Department of Mental Health over the last several years has had an initiative looking at outcome studies. Both consumer satisfaction and outcome studies are part of the outcome measures.

Consumer Satisfaction

Regular site visits monitor contract compliance, billing reviews, and certification site surveys, which include interviews with clients. Once a year consumer satisfaction surveys are conducted of all individuals who seek care during the month of April.

Outcome Studies

The Center for Substance Abuse Treatment (CSAT) has made funding available for states to conduct studies of the need for treatment of substance abuse in their communities. Substance Abuse Prevention and Treatment (SAPT) Block Grant funds have been dependent in part on documentation of the need for such services. Missouri, with assistance from the Research Triangle Institute designed a “family of studies” to provide reliable and valid data to estimate the prevalence of substance abuse treatment need, facilitate planning such treatment, and aid in the implementation of effective and cost-efficient services. The needs assessment in Missouri consisted of a series of six studies that included both primary data collection and secondary analysis of existing data. Findings from these studies were combined with what was known in the literature on treatment needs to provide a comprehensive picture.

Findings from quality assurance studies that assist the Division in determining its treatment programming and client needs include:

1. the Department's Consumer Satisfaction Survey;
2. the Treatment Outcomes and Performance Pilot Studies (TOPPS II);
3. the Outcome Assessment and Service Improvement System (OASIS);
4. the Initial Standardized Assessment Protocol (ISAP);
5. the State Treatment Needs Assessment Program Grant (STNAP); and
6. the State Prevention Needs Assessment Studies (funded by the Center for Substance Abuse Prevention).

These findings are being computerized on the web and are repeated on a regular basis.

Agency Profiles

The Division of Alcohol and Drug Abuse also develops profiles of individuals served.

Appeals Process

Following the Leake process, anyone who applies for services with Department of Mental Health has the right to appeal many aspects of their care, if they are not satisfied. If they are deemed not eligible for services, they may appeal. If they disagree with service recommendations on the service plan, they may appeal. If they are getting a service and the service is taken away or reduced, the consumer has the right to appeal.

The Department of Mental Health, Comprehensive Psychiatric Services utilizes different mechanisms to assure quality and appropriateness of care. These mechanisms include consumer satisfaction surveys, ombudsman activity, outcome studies, and agency profiles.

Quality Assurance Activities Currently Conducted

Consumer Satisfaction Surveys

Consumer satisfaction surveys are conducted annually. During the month of April, all consumers who receive services receive a consumer satisfaction form.

Ombudsman Activity

The Department of Mental Health is planning to pilot an Ombudsman program in one region of the state for the Divisions of Comprehensive Psychiatric Services and Alcohol and Drug Abuse before the end of the fiscal year.

Appeals Process

Following the Leake process, anyone who applies for services with THE Department of Mental Health, has the right to appeal many aspects of their care, if they are not satisfied. If they are deemed not eligible for services, they may appeal. If they disagree with service recommendations on the service plan, they may appeal. If they are getting a service and the service is taken away or reduced, the consumer has the right to appeal.

Outcome Studies

For those receiving case management, several outcome measures are used. The CPS Adult Outcomes Assessment Packet includes an adult status report and the Multnomah Community Ability Scale. This outcomes information is obtained at admission, annually, and at discharge. For children, Comprehensive Psychiatric Services conducts a Child/Youth Status Report and Child Behavior Checklist (CBCL) at admissions, six months, and discharge.

The Division is beginning to compare service providers based upon the outcome data that is being collected. Reports that describe findings from these activities are also being developed.

How Agency Would Develop Assessment Tool

Three elements should be included:

1. The provision of consumer choice of service options.
2. The agency's commitment to increasing capacity for appropriate housing and supports to serve people in the community. (Track record of budget support for this philosophy)
3. Improved consumer outcomes in domains relevant to successful community living (such as housing, employment, etc.)

Department of Mental Health • Division of Mental Retardation/ Developmental Disabilities

The Missouri Department of Mental Health, Division of Mental Retardation/ Developmental Disabilities (MRDD) has established a number of quality assurance and outcome measures. The following are some of the salient components of the outcome system of the Division of MRDD:

Quality Assurance Activities Currently Conducted

Some of the key quality assurance activities that are being conducted are:

Consumer Satisfaction

Consumer Satisfaction Survey:

- A random sample of individuals served by the Division of MR/DD (3% sample) are interviewed annually to identify their satisfaction with services.
- *Consumer Complaints*: Consumer complaints are investigated by the Department Consumer Affairs Office (Christine Squibb) and Client Rights (Bob Bryant).

Appeals Process

Following the Leake process, anyone who applies for services with Department of Mental Health, has the right to appeal many aspects of their care, if they are not satisfied. If they are deemed not eligible for services, they may appeal. If they disagree with service recommendations on the service plan, they may appeal. If they are getting a service and the service is taken away or reduced, the consumer has the right to appeal.

- *Consumer Family Directed Support:* An additional appeals process can be accessed for those in Consumer Family Directed Support. The parent policy partner acts as an advisor for the family, providing information and support regarding any/all appeals process.

Quality Enhancement

Several quality enhancement processes are conducted:

- *MOAIDD*: A group of parents and consumers regularly visits agencies and talks with individuals with disabilities served by the agency. The purpose of this visit is to assure that the person's rights are considered, their social relationships are fostered, the individuals are participating in their community, and that they have self-determination and choice in their lives. The essence of these visits is to assure certification principles are being carried out.

- *Quality Improvement Teams*: Each regional center has a quality improvement team to work with providers. The Division has a Quality Framework Task Force that is developing new guidelines for the quality improvement teams. Since July 2000, each regional center has at least one RN on their quality team to ensure the health of consumers.

- *Practice Guidelines Initiative:* This is a department wide initiative. The guidelines will provide consumer, families, practitioners, and DMH with guidance regarding the delivery of treatment, services, and supports. The goal is to improve quality, access, and continuity of care.

Ombudsman Activity: The Division of MR/DD has developed several ombudsman activities:

- *Consumer Complaints:* The Department Consumer Affairs Office and Client Rights Office assist individuals with complaints about services they have received.

- *Parent Policy Partners:* The Parent Policy Partners work with families in each of the regional centers. These family/staff can assist families in an advisory capacity.

- *Missouri Protection and Advocacy*: Missouri Protection and Advocacy serves in this role.

Outcome Studies: Outcome measures are currently under development.

- *Outcome Project:* The Division of MR/DD is currently developing outcomes with which consumers will evaluate the quality and effectiveness of the services they receive.

- *Missouri Quality Outcomes:* The Division of MR/DD is currently redesigning the Certification Principles in MR/DD. This will now include best practices to achieve optimal outcomes.

In addition, there is some compliance measures that have been instituted by the Division of MR/DD. These include Abuse and Neglect Investigations, Quality Improvement Teams, and Division of Medical Services quarterly review of waiver programs.

How Agency Would Develop Assessment Tool

The Division of MRDD had certification and survey staff until July 1, 2000. The survey staff, along with consumers, regional center staff, and other providers reviewed waiver programs to ensure that certification principles were being met.

The actual licensure surveys are now conducted through the DMH Office of Quality Management (formerly licensure and certification). Staff from the Office of Quality Management review health and safety aspects, and consumer legal rights. A document, *Core Requirements,* is being written. It will describe the review process. This document, which includes a section on consumer rights and responsibilities, will be used by providers and DMH staff.

The role of division staff, in relation to quality, is being revised as well. A new document, *Missouri Quality Outcomes,* was recently completed. This document describes the process and principles that will be followed by consumers, families, staff, and providers. The following list includes activities to develop additional quality assurance measures:

- Develop a tool to assess the quality of support services to persons with disabilities
- Maintain quality outcomes that support and improve the value of services provided to persons with disabilities
- Provide a consultative method of assessment emphasizing quality outcomes as a way to measure the quality of support services to persons with disabilities
- Offer a way of gathering information through observation, record review, interviews with persons supported, their families and support staff on the quality of support services
- Conduct data collection and research on how well support services are meeting quality outcomes for persons supported; to identify the support service strengths as well as areas for enhancement. This information can then be utilized in quality improvement planning and person-centered planning to enhance the quality of life for persons supported
- Develop training and technical assistance resources to ensure continued efforts in supporting persons with disabilities to have improved quality of life.

Department of Health • Bureau of Special Health Care Needs/ Adult Head Injury Program

The Department of Health, Bureau of Special Health Care Needs, Adult Head Injury Program utilizes different mechanisms to assure quality and appropriateness of care. The following enumerates the current and proposed quality assurance measures.

Quality Assurance Activities Currently Conducted

The Adult Head Injury Program has conducted consumer satisfaction surveys during the past year. Outcome studies and quality assurance activities are currently in the process of being developed by the Department of Health. Guidance for Service Coordinators and providers for knowing when to transition consumers out of current services to new services, so the consumer does not linger in services, is being examined. The Department of Health has developed reports that describe some of the findings from some of these activities.

How Agency Would Develop Assessment Tool

The Department of Health, Adult Head Injury Program, is currently looking at all of the areas listed in this question as possible outcome measures. In addition, infrastructure or environmental supports must be

looked at. A focus would be put on natural supports. The person-centered approach would be examined in developing this instrument, as well as natural and environmental supports.

The Division of Aging (DA) utilizes different mechanisms to assure quality and appropriateness of care. These mechanisms include quality assurance activities, consumer satisfaction surveys, ombudsman activity, outcome studies, and agency profiles.

Quality Assurance Activities Currently Conducted

Quality Assurance

Each agency under contract with DA receives technical assistance, provider training, and regular opportunities for policy updates through regional meetings hosted by DA. Additionally, each agency receives, at a minimum, an on-site evaluation of agency operations at least every two years. DA also utilizes Management Advisory Teams (MATs) to obtain input from field staff on a variety of topics, including proposals for improving services.

Consumer Satisfaction

DA currently has two formal processes to determine consumer satisfaction with service delivery. The first involves a ten-day follow up with new clients and clients transferred to a new provider. This contact ensures that services have been initiated according to information provided in the care plan and the annual reassessment visit and verifies that the current service plan remains appropriate to the person's needs. The case manager also assesses this issue any time the condition, circumstances, or situation of the individual changes significantly.

In addition, DA has a Provider Complaint process whereby complaints about in-home service or their aides are forwarded to the Provider Monitoring Unit in Central Office for review and necessary action.

Ombudsman Activity

The Long-Term Care Ombudsman Program assists individuals in choosing a long-term care facility, including referring them to the MCO Program to ensure that facility placement is the appropriate setting for them. The program also refers residents of facilities to the MCO Program if they wish to leave the facility or move from a nursing facility to a Residential Care Facility.

Outcome Studies

DA compiles and publishes the annual MCO report which illustrates the savings afforded by home and community based services as opposed to nursing facility placement. This report also details the number of pre-long term care screenings handled by staff and provides important demographic information for use in future program-planning efforts.

Agency Profiles

Certain requirements must be met for an in-home provider agency to receive a contract with DA. These include the following: agency manager must be at least 21 years of age, and be a registered nurse licensed in Missouri or have at least a bachelor of science or bachelor of arts degree; or be a licensed practical nurse currently licensed in Missouri with at least one year of experience with the direct care of the elderly, disabled and infirm; or have at least three years of experience with the direct care of the elderly, disabled and infirm.

How Agency Would Develop Assessment Tool

The Division of Aging Home and Community Services are currently initiating plans to assess consumer satisfaction. Effectiveness and quality care are program attributes, that should be defined first and foremost by consumers themselves. With definition of what consumers, caregivers, and helping professionals establish as measures of effectiveness in service delivery and support, DA would develop survey tools to capture this information. We would also engage other strategies to obtain feedback on programs, such as focus groups, random telephone calls, and home visits.

Quality Assurance Activities Currently Conducted

Several consumer satisfaction surveys with consumers have been conducted. Mississippi State University does the evaluation of the Older Blind Independent Living program. In response to a federal mandate, the Rehabilitation Council meets quarterly and public hearings are held at these meetings in the evening all over the state. The Assistant Deputy Director in charge of field operation acts as the designee agency ombudsman. A number of reports that describe evaluations are produced on a regular basis.

Recommendations:

The following are recommendations to address Activity 2:

1. Identify one department or other entity that will take the leadership on the development of outcome measures that will assure that services are effective and addressing the needs of individuals with disabilities. The assessment should be integrated into the existing outcome measures of each department. Any assessment instrument that is developed should have extensive consumer input.

2. Measure the rate of persons moving into the community at the end of each year. This should look at how many individuals, who are currently living in an institution but are waiting to move to the community, were moved into community settings. This evaluation should also look at the reasons why those who wanted to live in the community, but who are still in institutional settings, have not been moved to the community.

3. Develop a process evaluation that will assess whether the activities of this plan have been met. This evaluation should look at outcomes at the end of next year.

4. Develop a provider agency listing or profile that could be used by consumers. This profile will, where feasible, identify staff turnover, consumer residential movement, consumer satisfaction, and other factors that had been reported as important in assuring that the needs of the individual are best met. Assure that the listing is in a multimedia format (e.g., manual, CD-ROM, website) to best disseminate the information.

5. Identify the number and type of individuals trained on informed choices. Survey individuals trained on issues related to the Olmstead decision (e.g., informed choice) to determine what information they received and how they are putting this into practice.

6. Develop processes to interview individuals who entered the system during last year to determine if they had informed choice.

Timelines and Responsible Parties to Implement Recommendations:

The following table summarizes recommendations, identifies agency(ies) responsible for planning and initiating activities to realize each recommendation, and identifies the calendar year in which the results will be achieved. The code for the state agencies is:

- DESE- Department of Elementary and Secondary Education

- DVR- Division of Vocational Rehabilitation
- DMH- Department of Mental Health
- ADA- Division of Alcohol and Drug Abuse
- CPS- Division of Comprehensive Psychiatric Services
- MRDD- Division of Mental Retardation/Developmental Disabilities
- DOH- Department of Health
- AHIP- Adult Head Injury Program
- DSS- Department of Social Services
- DA- Division of Aging
- DMS- Division of Medical Services
- RSB- Rehabilitation Services for the Blind

Recommendations:

1. Identify one department or other entity that will take the leadership on the development of outcome measures that will assure that services are effective and addressing the needs of individuals with disabilities. The assessment should be integrated into the existing outcome measures of each department. Any assessment instrument that is developed should have extensive consumer input.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Commission will identify lead department to develop outcome.	Commission		x
Agencies will participate in the interagency development of outcome measures to assure services are effective and addressing the needs of individuals with disabilities	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		x

2. Measure the rate of persons moving into the community at the end of the year. This should look at how many individuals, who are currently living in an institution but are waiting to move to the community, were moved into community settings. This evaluation should also look at the reasons why those who wanted to live in the community, but who are still in institutional settings, have not been moved to the community.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02

Division of Comprehensive Psychiatric Services will measure the rate of community placement as outlined in this recommendation.	Div. CPS		x
DMH-MRDD will generate monthly waiting lists to track the rate individuals living in institutions are moved to community settings.	DMH-MRDD		x
Mo. Care Options Screening and Tracking Process	DSS-DA		x

3. Develop process evaluation that will assess whether the plan activities have been met. This evaluation should look at outcomes at the end of next year.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Lead agency will develop process evaluation measures.	(to be identified)	x	
Agencies will take part in the process evaluation recommended by the Olmstead Commission.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		x

4. Develop a provider agency listing or profile that could be used by consumers. This profile will, where feasible, identify staff turnover, consumer residential movement, consumer satisfaction, and other factors that had been reported as important in assuring that the needs of the individual are best met. Assure that the listing is in multimedia formats (e.g., manual, CD-ROM, website) to best disseminate the information.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Division of Comprehensive Psychiatric Services will participate in an interagency initiative to establish a consistent method to profile provider agencies.	DMH-CPS		x
DMRDD will develop a provider profile that describes DMRDD contracted providers for consumers using select, meaningful outcome data from the Missouri Quality Outcome Framework.	DMH-MRDD		x
Provide data from Home and Community Based Monitoring Unit	DA		x

5. Identify the number and type of individuals trained on informed choices. Survey individuals trained on issues related to the Olmstead decision (e.g., informed choice) to determine what information they received and how they are putting this into practice.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Agencies will identify the number of individuals trained on informed choices during the statewide teleconference training proposed in this document and participate in surveying those individuals.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		x
Agencies will ensure all service coordination staff and provider staff that provide service coordination, receive information on informed choices, and issues related to the Olmstead decision and have an opportunity to participate in training. When training is provided, a sign-in sheet will be utilized to document staff participation.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB	x	

6. Develop processes to interview individuals who entered the system during last year to determine if they had informed choice.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Division of Comprehensive Psychiatric Services will include questions about informed choice in the consumer satisfaction surveys it conducts on an annual basis.	DMH-CPS		x
DMH-MRDD will include questions on future consumer surveys that will indicate if individuals entering the system during the past year received information on their right to services in the most integrated setting that could meet their need.	DMH-MRDD		x
Enhance Missouri Care Options Screening Process	DA		x

Budget Action, Federal Action, and Statute Changes.

The following budget action, federal action, and/or statute changes are required to successfully complete the proposed activities.

Needed Budget Action:

DMH-MRDD

- Olmstead Waiting Lists to provide community placement to persons on waiting lists

Total Funding	$60,347,097
General Revenue	$21,636,028
Federal Funding	$38,711,069

- New Case Management Staff (128 FTE)

Total Funding	$5,559,558
General Revenue	$1,746,054
Federal Funding	$3,813,504

DSS-DA

Increase funding for staff activities and training as described.

Federal Action:

None required.

Statute Changes:

None required.

Activity No. 3: Identify the number of individuals with disabilities in the State of Missouri that are institutionalized.

Department of Mental Health, Division of Alcohol and Drug Abuse
Department of Mental Health, Comprehensive Psychiatric Services
Department of Mental Health, Division of Mental Retardation/Developmental Disabilities
Department of Social Services, Division of Aging

This activity focused on identifying the number of individuals with disabilities in the State of Missouri that are institutionalized. Each of the agencies that participated in this Commission and its activities did not have individuals in institutional settings. The Division of Aging in the Department of Social Services paid for services in institutional settings. The Department of Mental Health also funded institutional programs for the individuals they served. The following describe these programs.

One critical finding was that agency staff need to better define the term "institutionalization" and review how to more precisely measure these placement activities. The Commission found that there is a wealth of data on state operated facilities, but incomplete or conflicting information on publicly funded placements in private facilities. State agencies must act aggressively to review this population and the programs that serve them.

Department of Mental Health • Division of Alcohol and Drug Abuse

The Division of Alcohol and Drug Abuse projects that 9,187 will be served in community-based residential rehabilitation during FY'01. In residential treatment programs, a person receives around-the-clock care, seven days a week. Residential rehabilitation includes assessment, individual and group counseling, family counseling, participation in self-help groups, and other supportive measures designed to help a person live an alcohol and drug-free life.

Department of Mental Health • Comprehensive Psychiatric Services

The state-operated psychiatric facilities were treating 1429 individuals on June 1, 2000. Of these individuals, only 319 were classified as either voluntary or voluntary by guardian. Over two-thirds of the 319 individuals were committed by guardians (221 individuals or 69.2%) and 98 (30.8%) had committed by themselves. Of those committed voluntarily 53 (54.1%) have resided in the facility for less than six months and 44 (45.9%) for greater than six months. Of those who are committed by guardians, the majority had resided in state-operated inpatient facilities for more than six months (55.7%). For those under 18 years of age, however, 89.2% (73 out of 82 youth) had been in the state-operated facility for less than six months. Table 1 describes these findings.

Table 1. State-Operated Inpatient Facilities (as of June 1, 2000): Comprehensive Psychiatric Services

Age	Length of Stay	Voluntary by Self		Guardian	
Under 18	Less than 6 months	NA		73	33.0%
	Greater than 6 months	NA		9	4.1%
18-64	Less than 6 months	53	54.1%	25	11.3%
	Greater than 6 months	44	44.9%	104	47.1%

65 and Over	Less than 6 months	0		0	-
	Greater than 6 months	1	1.02%	10	4.5%
		98	**30.8%**	**221**	**69.2%**

The Division of MR/DD operates six habilitation centers throughout the state which provide institutional care for persons with mental retardation or developmental disabilities. During the past year, 1,322 consumers resided in these facilities. Figure 1 presents the FY 2000 consumer counts for habilitation centers. Approximately one-fourth of the residents reside in each of three habilitation centers: Bellefontaine (29.2%), Marshall (25.6%) and St. Louis DDTC (24.4%).

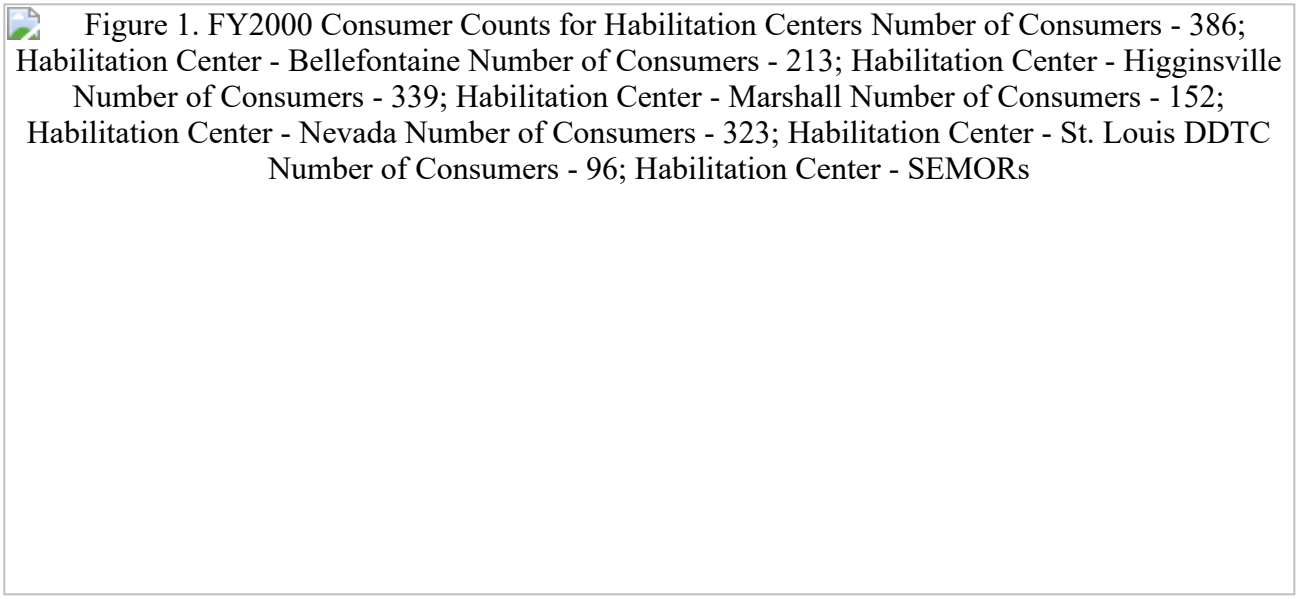


Figure 1. FY2000 Consumer Counts for Habilitation Centers Number of Consumers - 386; Habilitation Center - Bellefontaine Number of Consumers - 213; Habilitation Center - Higginsville Number of Consumers - 339; Habilitation Center - Marshall Number of Consumers - 152; Habilitation Center - Nevada Number of Consumers - 323; Habilitation Center - St. Louis DDTC Number of Consumers - 96; Habilitation Center - SEMORs

A comparison of those living in institutions with those in community placement can be found on Table 2.

Table 2. Persons Served in Institutional and Community Settings
Division of Mental Retardation/Developmental Disabilities

Type of Living Arrangement	**# of Providers**	**# of Consumers**
Persons in Institutions:		
State Operated Habilitation Centers (ICFs/MR)	6	1,322
Persons in the Community:		
State Operated Community Based Waiver	6	185
Contracted Facilities by size:		
1-3 Beds	70	88
4-8 Beds	321	1608
9-16 Beds	64	605
Over 16 Beds	146	568
ISL (3 or less)	212 (lead agencies)	2361
Total Community = 5415		

Total in State Operated ICFs/MR = 1322 Data as of 6/30/00

The budget allocations for FY 2001 for state habilitation centers can be found on Table 3.

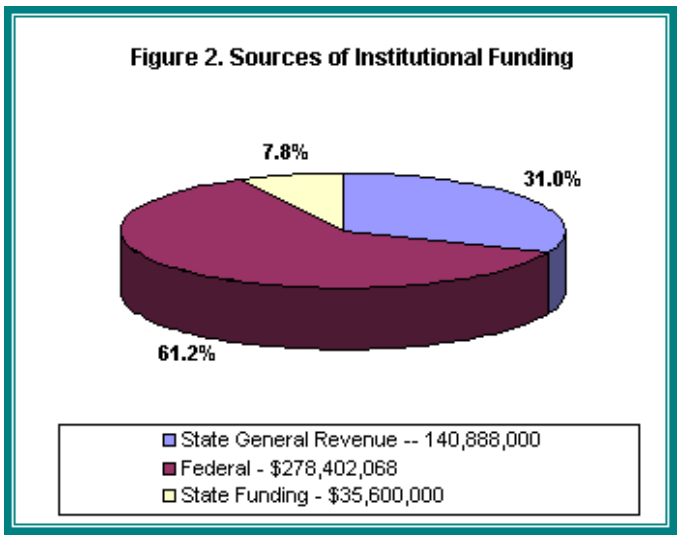
Table 3. Budget Allocations for FY'01 for State Habilitation Centers.
Division of Mental Retardation/Developmental Disabilities

Habilitation Centers	
General Revenue	$92,722,484
Federal	$3,900,846
Total	$96,623,330
Intensive Staffing (1)	
General Revenue	$145,189
Federal	$1,431,063
Total	$1,576,252
Community Support Staff (2)	
Federal	$850,988
Fuel & Utilities (3)	
General Revenue	$2,385,470

(1) Intensive staffing funds allow the Division of MRDD to meet staffing needs in the habilitation centers by providing adequate levels of staff to client ratio. Often times, the staff/client ratio is 1:1 and sometimes 2:1.
(2) Community Support Staff funding received by the habilitation centers helps support the operations of the habilitation centers, both on-campus and off-campus.
(3) Includes funding to allow the Division of MRDD's habilitation centers to purchase fuel and utilities, namely coal, oil, natural gas, water/sewer services, and electricity.

Budget data FY'2000-2001

Department of Social Services • Division of Aging



The total number of Department of Social Services Division of Aging Medicaid Recipients in facilities is 26,111. The core appropriations for the current year were $454,890,068. Of these funds, 31.0% were from state General Revenue ($140,888,000), 61.2% from federal sources ($278,402,068) and 7.8% from other state funding ($35,600,000). See Figure 2.

Activity No. 4: Identify the number of waiting lists for home and community-based services or consumer-directed care programs and evaluate the pace at which individuals move from these lists.

Department of Elementary and Secondary Education, Vocational Rehabilitation
Department of Mental Health, Division of Alcohol and Drug Abuse
Department of Mental Health, Division of Comprehensive Psychiatric Services
Department of Mental Health, Division of Mental Retardation/Developmental Disabilities
Department of Health, Bureau of Special Health Care Needs, Adult Head Injury Program
Department of Social Services, Division of Aging

Department of Elementary and Secondary Education • Vocational Rehabilitation

Each of the 21 Centers for Independent Living (CIL) maintains a waiting list. Each CIL is responsible for determining priority status on the waiting list based on such factors as the 18 point assessment total, risk factors regarding nursing home placement, and length of stay on the waiting list. Therefore, each CIL would have to be responsible for providing information regarding the pace at which individuals move from the waiting lists. The current verified/unverified number of individuals awaiting services is found in Table 1.

Table 1. Number of Persons with Disabilities on Waiting List

Waiting List	NME Program	IL Waiver Program	Total
Verified	209		
Unverified		60	
Total			269

Department of Mental Health • Division of Alcohol and Drug Abuse

Waiting list information is maintained by the Division of Alcohol and Drug Abuse's contracted providers. These agencies have procedures in place for admitting clients to treatment from the waiting list. The time period which individuals remain on a waiting list for treatment services varies. No individual, however, remains on a waiting list for 90 days or more. The estimated waiting period is three weeks.

Department of Mental Health • Comprehensive Psychiatric Services

The Division of Comprehensive Psychiatric Services does not operate any formal waiting lists. State Operated Inpatient Facilities admit all forensic and civil involuntary detentions regardless of current census. The nature of virtually all inpatient hospitalizations is emergency; therefore, waiting lists are not appropriate for this service.

In reference to Medicaid funded services administered by the Division of Comprehensive Services, Medicaid does not allow a waiting list. Although some of our contracted providers do have waiting lists at various times for state general revenue funded outpatient services (services that are not an entitlement), the Division does not compile these local lists.

The situation with regard to the Division's Supportive Community Living Program is more complex. The Supported Community Living (SCL) program provides funding for a variety of housing and residential alternatives. Our regional SCL offices report that they do not maintain waiting lists because they are able to place most referrals within 30 days. However, the lack of referrals who are awaiting placement is more likely a function of the general awareness of the limited resources available to the SCL program, and the limited availability of affordable housing, than it is an indication of the ability to adequately meet the need for supported community living services. Generally, the Division of Comprehensive Psychiatric Services' Supportive Community Living Offices report that they are able to place most individuals within 15 to 30 days of referral.

Table 2. Waiting Lists by Program 8/25/00

Residential Support	574
Consumer and Family Directed	1,620
Autism Services	732
Leave State Operated Habilitation Centers (ICFs/MR)	62

The Missouri Division of Mental Retardation/Developmental Disabilities maintains several waiting lists for services. (See Table 2.)

A current waiting list and a list from several months ago were provided identifying individuals waiting for residential supports and for individuals waiting to leave state operated habilitation centers. At the time this report was finalized, two periods of data were not available for Consumer and Family Directed Supports and Autism Services. One period of data was available for Consumer and Family Directed Supports.

Waiting to Leave State Operated Habilitation Centers

The first waiting list to be examined was the listing of those in a habilitation center who requested placement in the community. The way in which this list was examined was to look at those on the waiting list as of August 25, 2000 and compare them to those on the waiting list as of November 13, 2000. Table 3 describes the differences in the lists.

Table 3. Movement from Waiting Lists

Institution	8/25/00 Total	Inappropriate Placement on List	Guardian Opposed	Transfer to Another Institution	Consumer Withdrew Request	Added to List	Community Placement	11/13/00 Totals
Bellefontaine	22	1	2				1	18
Higginsville	17	11						6
Marshall	7		1	2				3
Nevada	0					1		1
DDTC	16					1		17
Southeast Mo.	0					1		1
Total	**62**							**46**

Another analysis looked at those still on the list in November 2000. The length of time that they had remained on the list was calculated.

Table 4. Length of Time on Waiting List: MRDD

Institution	<3 months	3-6 months	6-12 months	>12 months	Total 11/2000
Bellefontaine			11	7	18
Higginsville		6			6
Marshall			2	1	3
Nevada	1				1
DDTC	1	16			17
Southeast Mo.		1			1
Total	**2**	**23**	**13**	**8**	**46**

Waiting for Residential Support

The waiting lists of individuals who currently reside at home, but who are waiting for community residential supports were examined. The first list consisted of individuals who were on the waiting list as of May 23, 2000 and the second list included those on the waiting list as of September 30, 2000. There were 32 individuals added to the waiting list between these two dates and 33 taken off for a net loss of one person. Approximately 6% were removed from the waiting list over a 120-day period. (See Table 5.)

Table 5. Community Waiting List: MRDD

Region	May 24, 2000	People Added to List	People Taken Off the List	September 30, 2000
Albany	28	3	3	28
Kirksville	34	2	7	29
Hannibal	42	8	4	46
Kansas City	62	0	4	58
Joplin	61	6	4	63
Springfield	35	0	1	34
Rolla	60	13	6	67
Poplar Bluff	14	0	0	14
Sikeston	24	0	2	22
St. Louis	117	0	0	117
Central Missouri-Columbia	97	0	2	95
Total	**544**	**32**	**33**	**543**

Waiting for Consumer and Family Directed Supports

Table 5 is a summary of the list of persons waiting for Consumer and Family Directed Supports as of October 31, 2000. Although detailed comparative data was not available from an earlier or later period, it is noted that from August 25, 2000 (see Table 2 above) to October 31, 2000 (see Table 6 below) there was a net increase of 26 people statewide waiting for Consumer and Family Directed Supports.

Table 6. Consumer and Family Directed Supports Priority Waiting List: As of October 31, 2000

Region	Priority I Total[a]	Priority II Total[b]	Priority III Total[c]	Total Count
Albany	9	50	4	63
Kirksville	5	2	1	8
Hannibal	0	7	7	14
Kansas City	105	355	87	547
Joplin	7	22	3	32
Springfield	50	37	16	103

Rolla	8	91	31	130
Poplar Bluff	9	28	8	45
Sikeston	7	15	13	35
St. Louis	151	348	96	595
Central Missouri-Columbia	11	57	6	74
Total	**362**	**1012**	**272**	**1646**

a. Priority I: Person is homeless; physical/emotional, mental health is in jeopardy; or person is a threat to self or others.
b. Priority II: Family support is not available; or primary caregiver is elderly.
c. Priority III: Consumer or family wants to direct own services; receiving residential services

Waiting List Data

The Department of Mental Health is in the process of designing a new information system. As this new system is designed, DMRDD will be requesting that the new system enhance the current process for maintaining waiting lists so that comparative data and reports are more readily available.

Department of Health • Bureau of Special Health Care Needs/ Adult Head Injury Program

There is currently no waiting list.

Department of Social Services • Division of Aging

Table 7. Social Service Block Grant Waiting List

As of:	Number
09/99	3,371
04/00	3,239
09/00	3,270

Current number of persons on high Priority waiting list – 578

(Note: These numbers represent only those persons who have actually contacted Division of Aging to request assistance. The total number of persons who could benefit from in-home services may be significantly greater.)

There is no waiting list for Medicaid funded programs. Social Service Block Grant (SSBG) funded programs do have waiting lists, which are reviewed at least annually or as frequently as service availability warrants. Persons are placed on the waiting list as high, medium, or low priority according to various factors such as level of care, lack of other supports, homebound status, protective service need, financial resources, and others. This funding stream has declined in recent years due to federal budget cuts and the increased use of SSBG dollars to fund services for Medicaid spend-down consumers and presumptive eligibility for Missouri

Care Options consumers during period of Medicaid ineligibility. The Social Service Block Grant waiting list as of three dates is presented in Table 7.

Activity No. 5: Examine whether existing programs and services provide individuals with disabilities who may be eligible for community-based treatment with information regarding this option.

Informed Consent

Discussion:

Background Information: The Olmstead decision is based on the premise that informed choices are required to allow the consumer with a disability to determine for themselves if they wish to live in an institutional setting or in the community.

General Public Comments: Participants at the Public Hearings and Commission meetings commented on issues related to informed consent including who should conduct the informed consent, the need for an ombudsman and the professionals' opinion.

I've been disabled since June, so I don't know any of this. So I need to be informed. How can I be informed? I need to be told everything. I don't know all the technicalities. I don't know all the ways and means. I don't know anything about anything. This is going to have to be explained to me completely. How?... If you don't know what choice you have, you have no choice. (Springfield)

One of the main principles in the Olmstead decision was that there should be informed choice. If a professional believes that a person should remain in the community and the person wants to remain in the community, reasonable accommodations should be made to make this possible. The same ruling applies to individuals who currently reside in institutions. In the Cape Girardeau public hearing, this issue was raised. *And then – then another issue is what we kind of wondered about is if the nursing homes and that are really giving our consumers the informed choice.* Continuing, this speaker felt that sometimes physicians also did not know about this choice and recommended nursing homes too quickly. *So these consumers kind of afraid because they put so much power in this doctor that, you know, they think that they're not capable when they are to live on their own so it may be a matter of educating physicians and so forth.* Another speaker in Cape Girardeau stressed that placement *should be the family's decision along with the appropriate professionals to ensure that.*

Informed choices may require *access to legal rights.* One speaker in Springfield noted that *They need attorneys that will stand behind them and say no, no, no you must not do that. You are violating this person's civil rights. She has a right.* Another presenter also noted the need to have informed choice about the community services that are available. *If your parent is looking at going into an institution, they need to be informed that if they could benefit from having maybe Meals on Wheels, someone to come in and help them shop or bathe, these services could be provided in an effective manner in their homes, that that is their choice. This is all about choice. (*Springfield). One problem can be the timing of any decision to institutionalize. *That's the*

problem. People have to make the choice so fast and usually they are so scared and the family is wanting to just get it over with and it's done very quickly (Springfield).

In Springfield, how to provide informed choices was posed as a challenge. One speaker said *that the stakeholders group has really wrestled with this since February when they had their very first meeting. One of the decisions they thought they really could benefit from in the long run as well as the short run would be if they could train everybody who are the direct service people who see the individuals with disabilities and we're not just talking about in nursing homes, but those who might be in danger of going into the nursing home. ...If they knew what's available across-the-board depending on what your disability was and what your age was, and if they could present that information so they could present informed choices so they would know what they could pick from, then they would be in a better position to say what they want to do and know that if you choose the nursing home how, you could choose to get out of it later.*

Another speaker noted that there was a need for *some ombudsman, someone who is trained, all trained the same is going to go in and we're going to know that everyone in that place had informed choice. .. There needs to be some sort of accountability for professionals like myself who are working in rehab units to make sure that we're doing an informed choice, that we're all along our programs are built around choice and that choice is being honored* (Springfield).

One further issue brought up about informed consent was the opinion of the treating professional and the consumer's right to disagree with their decision. *We don't want to forget if your treating professional doesn't think that's the appropriate setting you have a right to change treating professionals. If you have your own guardianship and the doctor says no, I want you to stay in that nursing home, maybe this is the nursing home's doctor... so if you can find a different doctor, you have a right to a different doctor* (Springfield).

Training of staff on how to assure consumers have informed choices is important. *We were to review the agency training for frontline staff in the area of informed choices to assure consumers are aware of their option to live in the most integrated setting appropriate to their needs. For that particular section it was not addressed by the agency.* (Commission Hearing)

Summary of Practices Related to Informed Choice by Agency

The following summary reflects the comments of the Division of Comprehensive Psychiatric Services, Rehabilitation Services for the Blind, Department of Health, Division of Aging, Division of Alcohol and Drug Abuse, Division of Vocational Rehabilitation, and Division of Mental Retardation and Developmental Disabilities on the issue of informed consent. There is significant variance across the agencies surveyed about the following questions from the Agency Survey. Three questions were asked:

What information does each person who comes into your program receive about this (Olmstead) option? How is this told to the person and/or guardian?

What information do you give to people who are currently institutionalized about the Olmstead option? How is this told to the person and/or guardian?

Does your agency provide training to those who offer consumer choices of residential settings?

Department of Elementary and Secondary Education, Division of Vocational Rehabilitation

Information each person entering program receives about Olmstead

The Division of Vocational Rehabilitation operates a consumer-directed program through the 21 Centers for Independent Living (CILs). Each center is responsible for developing and providing information in alternative

formats as necessary. Each center has its own brochure and is responsible for the manner in which other needed information is conveyed.

Information given to people who are currently institutionalized

The Division of Vocational Rehabilitation cannot provide Personal Care Assistant (PCA) services to clients in an institutional setting. However, CILs have information readily available for institutionalized individuals who desire information regarding transitioning to the community.

Current training

Each of the 21 individual centers is responsible for training consumers on how to supervise and train their personal attendants. The Plan of Care developed by the Assessment Team includes a training plan based on each consumer's needs. Each consumer can choose his own attendant as long as it is not a spouse. The consumer is then responsible for training that attendant. Based on informed choice, CILs provide and coordinate additional training for consumers and their attendants.

Department of Mental Health, Division of Alcohol and Drug Abuse

Information each person entering program receives about Olmstead

Since the Division of Alcohol and Drug Abuse's treatment services are provided in a community-based setting and in the least restrictive environment possible, the Olmstead decision is not referred to by name. All treatment providers are required to have policies and procedures that enhance and protect the human, civil, constitutional, and statutory rights of each client. A notice of clients rights, opinions, recommendations, and grievances is posted prominently in all certified treatment agencies. (Refer to *The Certification Standards for Alcohol and Drug Abuse Programs* for detailed information pertaining to client rights.)

Current training

The Division of Alcohol and Drug Abuse conducts two annual training events for administrative and direct care staff which cover a variety of topics including information about state and federal guidelines, which impact the operation of treatment programs. Ongoing training needs are assessed and specialized training events are held as needed. In addition, ongoing training is provided at locations throughout the state by the Mid-America Addiction Technology Transfer Center, Kansas City, Missouri. The Addictions Technology Transfer Center consults with Division and provider staff to ensure that the training/education needs are met.

Department of Mental Health, Division of Comprehensive Psychiatric Services

Information each person entering program receives about Olmstead

The Division of Comprehensive Psychiatric Services promotes informed consumer choice, and has been actively developing community-based services and supports, although Olmstead Decision is not referred to by name. The treatment planning process is the time when options are discussed with both the individual in treatment and the guardian. The individual and the guardian both sign the treatment plan. The goals of the treatment plan are individualized according to individual needs. When an individual is referred for Supported Community Living, the staff member assigned to that referral works with the treatment team and the individual referred to explore community options consistent with the individual's needs. The individual selects the program they want from among those options.

Information given to people who are currently institutionalized

The treatment planning process is the time when options are discussed with both the individual in treatment and the guardian. The individual and the guardian both sign the treatment plan. The goals of the treatment plan are individualized according to individual needs.

Current training

The Division of Comprehensive Psychiatric Service provides training to inpatient staff who offer choices to consumers and is in the process of developing training for staff of contract providers who offer options. That training does not currently contain information specific to the Olmstead Decision.

Department of Mental Health, Division of Mental Retardation/Developmental Disabilities

Information each person entering program receives about Olmstead

When a person applies for services at the Division of Mental Retardation and Developmental Disabilities (MRDD), they are given a packet of information that includes a Waiver Fact Sheet. This one-page (front & back) sheet describes home and community based services and includes information on eligibility and rights to due process. A memo was sent to Regional Centers on August 19, 1999, that instructed staff to begin using the Waiver Fact Sheet to inform consumers and families of community based services. As needed, staff was asked to translate or further explain the information to individuals and or guardians.

Information given to people who are currently institutionalized

At the Division of MRDD Habilitation Centers, staff has been asked to inform each resident and guardian/family about the option of services in the community. As part of the process, they have been instructed to give the individual a copy of the Waiver Fact Sheet. A memo was sent to Habilitation Centers on February 9, 2000. Center staff was instructed to ensure that all residents and/or their guardians are given information and have an opportunity to make an informed choice. To avoid confusing or alarming people, staff have been instructed to present the information in the manner that would make it most clear to each individual. Staff was discouraged from simply mailing the information.

The Division of MRDD has a brochure, *"Individual Rights of Persons Receiving Services from the Division of Mental Retardation and Developmental Disabilities."* A request has been made that this brochure be revised under Section 1. (dot point #6) to say, "To receive services and supports in the most integrated setting that appropriately meets the person's need as determined by the person's support team. The team may include, but not be limited to, the person, parents, guardian or authorized representative." *A Fact Sheet, Assuring Access to Community Living for the Disabled,* was made available to field staff in August. The Fact Sheet was intended to summarize the Olmstead Decision for staff who must explain the decision to consumers and families. Copies of the document could also be given to consumers, families, or guardians.

Current training

Waiver training is provided to new staff by Regional Centers and Habilitation Centers. Since implementing the first Home and Community-Based Waiver (HCBW) in 1989, the Division's service system and philosophy has focused on community-based services and services in the most integrated setting. In January 2000, a revised waiver manual was distributed to all Regional Center service coordinators. The manual is also on the Internet, http://www.medicaid.state.mo.us/ and will soon be on the Division's Intranet. Training is provided from time to time to service coordinators by central office staff to update service coordinators on Medicaid programs or changes to the HCBW. Most recently, the central office arranged a videoconference to improve staff knowledge of state plan personal care services and waiver services authorized by Divisions of Aging, Vocational Rehabilitation, and Bureau of Special Health Care Needs. The training included staff from the Division of Medical Services and the Division of Aging. Working to coordinate services with other agencies was stressed. These services are often used in conjunction with the MRDD waiver services and are critical to

supporting people in the community. The videoconference was conducted on October 4. Other state plan services often needed by persons in the Division of MRDD service system were also discussed. The session was videotaped and notes and follow-up information was posted on the DMH Intranet for staff.

Department of Health, Bureau of Special Health Care Needs, Adult Head Injury Program

Information each person entering program receives about Olmstead

The Department of Health, Adult Head Injury Program Service Coordinator covers general information about Olmstead Act at the initial service coordination meeting, since the goal of the program is to assist individuals in their effort to live independently.

Information given to people who are currently institutionalized

The Department of Health does not provide direct institutional care. Since there is no institutional care, there is no specific information given.

Current training

General information is given by Service Coordinators to people who are currently institutionalized about the Olmstead option.

Department of Social Services, Division of Aging

Information each person entering program receives about Olmstead

Since 1992, the Division of Aging (DA) has utilized the Missouri Care Options (MCO) program to screen individuals who are considering nursing facility placement and assess their ability to remain in the community with services. Upon initial request or referral for services from Division of Aging, all potential options are explained to an individual and/or their representative. This includes both services available within the community as well as those offered through institutional care. Protective services are available for persons at risk of abuse, neglect, or exploitation.

Information given to people who are currently institutionalized

The same information is provided to institutionalized persons upon request. DA tracks individuals who enter a nursing facility for short-term stays in order to assist with transition back to the community, whenever possible.

Current training

DA has partnered with hospitals, clinics and other community sites to base field staff in settings that are easily accessible for seniors and persons with disabilities aged 18-59. The Community Outreach Initiative also provides DA with the ability to arrange necessary services in a more timely manner. The Division prints and distributes several brochures which explain programs and services available. In addition, DA publishes the *Missouri Guide for Seniors* annually as a comprehensive directory of the many programs, resources, and services available to seniors and persons with disabilities. Selected materials are also being translated into Spanish and Russian languages to provide written information to non-English speaking populations.

DA also operates a statewide, toll free number for information and Referral (I & R). This number is publicized through a variety of means and is a strategic part of our method of dissemination of program and resource information. DA also partners with the ten Area Agencies on Aging (AAAs) to provide information and referral activities within each of their regions. In addition, DA has partnered with the University of Missouri-Columbia

(UMC) to utilize the Community Connection database for the Shared Care program. Shared Care is a system by which caregivers may access information about programs and services to assist them in caring for a loved one. Community Connection is a comprehensive, web-based directory of providers, resources, social service agencies, and others who provide assistance to caregivers. Ongoing training is provided to DA staff regarding case management activities, including agency policies in relation to the Olmstead Decision.

Department of Social Services, Rehabilitation Services for the Blind (RSB)

Information each person entering program receives about Olmstead

Rehabilitation Services for the Blind staff inform consumers who are blind or who have visual impairment about other appropriate resources for independent living. Consumers served by RSB are typically living in their homes. Staff do not have decision-making authority over or funding for institutional placements.

Identification of Barriers and Recommendations from the Olmstead Committees:

Following are barriers and related recommendations from the Olmstead Committees related to informed consent.

Barriers: There are many people in institutions who qualify for and could use the existing home and community-based options, but they are not informed of those options.

Recommendations:

1. State agencies should improve the assessment and screening process done before a person enters an institution and periodically thereafter. Add informed choice components to assure the individual knows all of the options and rights.

2. Staff must review all applications for nursing home admission or institutional placement. Additional screening and training to staff to screen for disability and refer persons to DA, CILs, CMHCs, Regional Centers, or at least provide them information upfront about service options that might be available before the person is admitted to the nursing home or other segregated settings should be developed.

Barrier: Most individuals are not informed about the services available in community or institutional settings.

Recommendation:

The commission should designate a lead agency or entity that would be responsible for arranging for a single source document that outlines all of the services currently available for persons with disabilities to be made available in alternative, accessible formats and be kept current.

Barrier: It will be difficult to be sure that the informed consent process was adequately explained.

Recommendation:

A satisfaction survey process should also be developed to include monitoring and

incorporating into an oversight process (i.e., ombudsman). Contracted services

would also be included in this requirement.

Barrier: State agency case-managers, hospital discharge planners, and other providers do not know of the community options and/or make assumptions about an individual's ability to live in the community.

Recommendations:

1. Statewide training should be implemented to assure that all providers and state agency staff are aware of Olmstead and its implications. The Olmstead Task Force will take the lead on this initiative. Consumer input should assist in identifying the type of training and its content (e.g., video, CD-Rom). There is a wide audience for this training:

a) Those workers employed by the Divisions of Aging, Family Services, Medical Services, Comprehensive Psychiatric Services, Alcohol & Drug Abuse, MRDD, Vocational Rehabilitation, State Schools and Sheltered Workshops, the Bureau of Special Health Care Needs and any state funded entity providing services to eligible persons with disabilities must participate in a one-day statewide training conference and periodic follow-up training events.

b) Those workers employed by vendors contracting to provide services for the State Divisions and Agencies (i.e. Home health agency staff; hospital discharge planners and social service directors; private habilitation center and ICF-MR workers; nursing home administrators and social service directors; direct service personnel from the Area Agencies on Aging, the University of Missouri Extension Service, Centers for Independent Living, public administrators and other providers) must participate in the same training conference and follow-up training events.

c) At each county site, trained volunteers and staff, hosts and discussion leaders, will be representatives from the local Center for Independent Living, AARP, People First, DD Regional Advisory Council, Brain Injury Association and any other community-based service and/or advocacy organizations. Wherever possible, individuals currently living in the community with state supports who have also lived in institutional settings will be on hand to share their first-hand experiences.

2. This training session should be statewide. Training efforts should encourage networking with agencies that provide services and get information (e.g., how to get Personal Care Assistant, transportation). Each agency is responsible for obtaining continuing education accreditation for their training programs.

Barrier: There is a significant turnover in state providers and state staff. Due to this turnover, there will be a continuous need for training of providers and state staff.

Recommendation: State agencies should develop and conduct statewide train-the-trainer sessions. Resource manuals will be developed to allow those trained to conduct training in their own region. Consumer input must be a part of this training effort. The material can also be available on the website, in a manual, and on CD-ROM to assure that all individuals receive the training about informed choice.

Barrier: There are many consumers who have questions about their rights and also who do not know where to turn for answers.

Recommendation: A 1-800 hotline or 211 number should be disseminated. Information needs to be marketed to the public to reach those that are not currently in programs.

Barrier: It may be hard to determine if a true informed consent process was conducted with persons with disabilities who seek services.

Recommendation: A Leave Behind Letter from a State Authority and the Informed Choice Sign-Off forms and brochures explaining the details for accessing state services will be provided by each government entity.

Recommendation: The state agencies should develop a verification process with the agencies to assure that informed choices was provided.

Barrier: Often decisions are made without the assistance of an advocate for the individual with a disability. The individual with a disability may feel overwhelmed and need someone to advocate for them.

Recommendation:

This multidisciplinary team shall be composed of at least the following: a professional as required by law and an independent living advocate (a person knowledgeable about independent living). An additional advocate of the person with disabilities' choice may be included if he/she so chooses.

Barrier: Individuals often do not understand the grievance and/or appeal process.

Recommendation: A clearly defined appeal procedure shall be available to all

participants in state programs. The steps to ask for an appeal should be clear and easy to follow. As a part of the informed choice process, each participant must be informed about these procedures and where they may receive assistance with the appeal and grievance process.

Timelines and Responsible Parties to Implement Recommendations:

The following table summarizes recommendations, identifies agency(ies) responsible for planning and initiating activities to realize each recommendation, and identifies the calendar year in which the results will be achieved: The code for state agencies is:

- DESE- Department of Elementary and Secondary Education

- DVR- Division of Vocational Rehabilitation
- DMH- Department of Mental Health
- ADA- Division of Alcohol and Drug Abuse
- CPS- Division of Comprehensive Psychiatric Services
- MRDD- Division of Mental Retardation/Developmental Disabilities
- DOH- Department of Health
- AHIP- Adult Head Injury Program
- DSS- Department of Social Services
- DA- Division of Aging
- DMS- Division of Medical Services
- RSB- Rehabilitation Services for the Blind

Recommendations:

1a. Improve the assessment and screening process done before a person enters an institution and periodically thereafter. Add informed choice components to assure the individual knows all of the options and rights.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Enhance staff training and revise MO Care Options form(s)	DSS-DA	X	X
DMRDD will continue to screen persons for the appropriateness of community services versus institutional services and will continue to inform persons seeking institutional services about alternative community services.	DMH-MRDD	X	

1b. Staff must review all applications for nursing home admission or institutional placement, including ICF/MRs. Increase the screening and training so that these staff can screen for disability and refer persons to DA, CILs, CMHCs, Regional Centers, or at least provide them information upfront about service options that might be available before the person is admitted to the nursing home or other segregated settings.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Strengthening existing systems to assure payments are not made prior to following protocol.	DSS-DMS	X	
Enhance existing systems for institutional screening processes.	DSS-DA	X	
Division of Comprehensive Psychiatric Services will participate in training related to referral to Community Mental Health Centers	DMH-CPS	X	
DMRDD will make information and training on the DMRDD service system and referral process available to Division of Aging staff who answer inquiries regarding potential nursing home or ICF/MR admissions and who process applications.	DMH-MRDD	X	
Conduct state agency assessment on services available for persons with disabilities. Each agency is responsible for their material.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		X

2. The commission should designate a lead agency or entity that would be responsible for arranging for a single source document that outlines all of the services currently available for persons with disabilities to be made available in alternative, accessible formats and be kept current.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Agencies will participate in the development of the single source document.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		X

3. A satisfaction survey process should also be developed to include monitoring and incorporating into an oversight process (i.e., ombudsman). Contracted services would also be included in this requirement.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Division of Comprehensive Psychiatric will incorporate questions regarding informed choice into its consumer satisfaction process and participate in the Department of Mental Health's pilot ombudsman program.	DMH-CPS		X
DMH-MRDD will incorporate monitoring and oversight questions in future consumer satisfaction surveys.	DMH-MRDD	X	

4a. Each department should implement statewide training to assure that all providers and state agency staff are aware of Olmstead and its implications. Consumer input would be invaluable in developing the training. To the extent possible, intra-agency training programs should be developed.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Agencies will participate in developing their statewide training and include both state and contract provider staff. Intra-agency programs will be developed where appropriate. All training programs should be on-going because of the turnover in staff and updated because of the changes in rules and laws.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		X

4b. This training session should be statewide. Training efforts should encourage networking with agencies that provide services and get information (e.g., how to get Personal Care Assistant, transportation). Each agency is responsible for obtaining continuing education accreditation for their training programs.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Agencies will participate in the statewide training and include both state and contract provider staff.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA		X

	DSS-DMS DSS-RSB		

5. State agencies should develop and conduct statewide train-the-trainer session. Resource manuals will be developed to allow those trained to conduct training in their own region. Consumer input must be a part of this training effort. The material can also be available on the website, in a manual, and on CD-ROM to assure that all individuals receive the training about informed choice.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Agencies will participate in the statewide training and include both state and contract provider staff.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		X

6. A 1-800 hotline or 211 number should be disseminated. Information needs to be marketed to the public to reach those that are not currently in programs.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Agencies will participate in disseminating 1-800 hotline numbers as designated by the Olmstead Commission.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB	X	

7a. A Leave Behind Letter from a State Authority and the Informed Choice Sign-Off forms and brochures explaining the details for accessing state services will be provided by each government entity.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02

Agencies will distribute the “Leave Behind Letter” to individuals with its treatment system who are eligible when it is finalized.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		X

7b. The state agencies should develop a verification process with the agencies to assure that informed choices were provided.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Agencies will incorporate a verification process into the licensure, certification, and monitoring processes for which it is responsible.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		X
DMH-MRDD regional center staff will continue to ask consumers/ families/guardians to sign a statement documenting their choice of receiving DMH-MRDD HCBW Services or institutional services, and to sign a statement documenting their choice of each waiver service provider.	DMH-MRDD	X	
DMH-MRDD state operated habilitation center staff will document in the individual’s record when community options are discussed with the individual/family/guardian, and the choice the individual/ family/guardian makes.	DMH-MRDD	X	

8. This multidisciplinary team shall be composed of at least the following: a professional as required by law and an independent living advocate (a person knowledgeable about independent living). An additional advocate of the person with disabilities’ choice may be included if he/she so chooses.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Multidisciplinary team will participate in determining eligibility for	DESE-DVR	X	

community-based services. Persons may choose an independent living advocate or any other advocate of their choice to participate in the person-centered plan process.	DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB		
State treatment professionals with DMRDD will participate in determining eligibility for community-based services that are accessed through DMRDD Regional Centers. Persons may choose an independent living advocate or any other advocate of their choice to participate in the person-centered plan process.	DMH-MRDD	X	

9. A clearly defined appeal procedure shall be available to all participants in state programs. As a part of the informed choice process, each participant must be informed about that procedure and where they may receive assistance with the appeal and grievance process.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Agencies will continue to assure that all clients are aware of appeal processes.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSB	X	
Will assure that state material regarding appeal process was provided to clients and documented in the client's medical record.	DOH		x

NOTE: It was recommended that adding educational or awareness component to MRDD for persons who may have been denied services in the past due to changes in the eligibility criteria.

Budget Action, Federal Action, and Statute Changes.

Needed Budget Action:

- A toll free informational phone hotline should be developed and marketed.
- Training for all agency and provider staff.

Federal Action:

None required.

Statute Changes:

- 1B. Screening for all nursing home applications.

Activity No. 6: Recommend any modifications or changes that may be needed to improve existing home and community-based services and consumer-directed care programs.

Background Discussion:

If a person moves from an institutional setting to the community, there are many challenges that must be faced. The person has to find an affordable, adequate place to live. They must have the funding for a rental deposit. Then, they must have furniture, utility deposits, and enough money to start their household. Often when living in an institution, the person must relinquish their Social Security payment to the institution. This means when the person leaves the institution, they have no funding to be able to live in the community.

General Public Comments:

The participants to the Public Hearings made numerous comments about the transitioning of individuals with disabilities who are institutionalized and who are eligible for community-based treatment in community-based settings. Many of these comments focused on the needs of these individuals to live a full live in the community.

I had shortly after my brain injury 21 years ago now I lived in a nursing home for awhile. It was a horrendous experience until I lived on a psych ward for over a year and that was a more horrendous experience. I was very luck. I had the support of services for independent living, the local independent living center here in Columbia that helped me get back into the community and I also had family support. Most of the people I work with now don't have that. (Columbia)

If a person moves from an institution to a community setting, there is a period of time in which exceptional costs and support may be required. These can include startup money, moving expenses, and first month's payment. Homes frequently must be modified. Other kinds of temporary, one-time payments must be addressed. One speaker estimated that *you're looking probably at over a thousand dollars to start off that these people have no way of saving up.* (Cape Girardeau). One Kansas City speaker described the issues *Yet are starting out with no credit ratings for deposits and lease signing, no home furnishings to set up a household. Once a home is established, nothing to do during the day, employment* (Kansas City).

Sometimes the services are not available in the community. This means that the person must enter or remain in the nursing home. *Basically what they all said was we can provide you with a nursing home, but we can't provide you with anything in the community* (Columbia).

Even little things can make a difference in living in the community. In the Cape Girardeau hearing, this sentiment was presented. *I mean we've been fortunate enough to get that stuff now but if we would get more people at it we might have a hard time coming up with a bed and a mattress, forks and spoons and pans.*

State Agency Information:

The summary of comments reflect the comments of the Division of Comprehensive Psychiatric Services, Rehabilitation Services for the Blind, Department of Health, Division of Aging, Division of Alcohol and Drug Abuse, Division of Vocational Rehabilitation, and Division of Mental Retardation and Developmental Disabilities. There is significant variance across the agencies surveyed about the following questions from the Agency Survey. There were four issues discussed on the surveys that will be addressed here. These include:

- **If someone is in an institution returns to the community, can you describe the current process for this transition?**
- **What types of additional community supports and funding are needed for institutionalized individuals to return to the community?**
- **What would the ideal process for transitioning individuals with disabilities who are institutionalized and who are eligible for community-based treatment into community-based treatment settings?**
- **How do you determine if an individual is capable of living in a non-institutional setting? What processes do you have in place to determine this capability?**

The responses for each of the state agencies will follow. Each question is sequentially addressed in the agency descriptions.

Department of Elementary and Secondary Education, Division of Vocational Rehabilitation.

Current process for transition from an institutional setting to the community: The transition is usually from a nursing home. The center staff completes the assessment and identifies needs of the consumer (housing, attendant, training, utilities, furniture, etc.). It is important to determine not only if a consumer can live independently in the community with support, but is capable of self-directing his or her own care. The current time of transition can be a matter of days to a few months depending on the amount of support the consumer already has in place (e.g., family, living arrangements, attendant trained and ready, etc.).

Additional supports needed for transition: Additional services could come from expanding the Independent Living Waiver. Additional support could come from amending the state plan to allow cognitively impaired consumers to select a "designee" to provide the consumer with care support services.

Ideal process for transitioning individuals with disabilities: People in nursing homes (facilities) need to be able to set aside some of their Social Security check to provide some funds to set up housekeeping when it is time to re-establish themselves in the community. Nursing home (facility) residents are required to give up their assets when they enter the facility in order to qualify for Medicaid. Therefore, the consumers are unable to leave the facility when they are ready to transition to the community. Also, the Medicaid State Plan (MSP) only allows a maximum number of hours of personal care per month. Consumers who require more services must access additional services through the IL Waiver. However, there is currently a cap of 470 people on the waiver. One option to provide services to additional consumers would be to amend the IL Waiver by increasing the capacity to enable more consumers to access services beyond the scope of the MSP.

How an individual is determined capable of living in a non-institutional setting: When leaving the nursing home, each center completes an 18 point assessment (the same tool as the Division of Aging). A team consisting of a center staff member (independent living specialist), a physical therapist/occupational therapist/nurse, and the consumer complete the assessment and determine needs. The Assistant Director, PAS, (DVR staff member) must approve the Plan of Care.

Department of Mental Health, Division of Alcohol and Drug Abused.

Current process for transition from an institutional setting to the community: The Division of Alcohol and Drug Abuse funds 96-hour involuntary commitment beds for substance abuse consumers in St. Louis at St. Louis Metropolitan Psychiatric Rehabilitation Center (five beds) and at Western Missouri Mental Health Center in Kansas City (five beds). These are the only Division-funded services that occur in a state institution and are for the detention and assessment of persons who present a likelihood of serious harm to themselves or others as a result of alcohol or drug abuse or both. The commitment is for a period not to exceed 96 hours. The assessment determines if further treatment is needed. If so, a referral is arranged through voluntary means or a court order.

Additional supports needed for transition: Not applicable

Ideal process for transitioning individuals with disabilities: Not applicable

How determine if an individual is capable of living in a non-institutional setting: Not applicable.

Department of Mental Health, Comprehensive Psychiatric Services.

Current process for transition from an institutional setting to the community: For persons who are hospitalized and persons in the Community Psychiatric Rehabilitation Consumer (CPRC) Program in the community, the treatment planning process involves the following: a quarterly review and an annual reassessment that provide for assessing when the individual is ready for a more integrated community setting and the process by which the transition will be made. In both cases, the assessment process is multidisciplinary. In the hospital it includes re-evaluation by a psychiatrist, nurse, and social worker. In the community it involves re-evaluation by staff from case management and psychiatry. The treatment plan must be rewritten at least annually or when any substantial changes in the individual's condition or treatment occur, and is updated quarterly. The treatment planning process is multidisciplinary and also includes participation by the person receiving services. Treatment plans commonly address skills that need to be developed to allow a person to move to more integrated settings such as budgeting, activities of daily living, and housekeeping. Treatment plans are always reviewed with the person receiving services and their signature is requested indicating their review.

Specific to children, transition may include visits back and forth between the institution and community-based treatment setting according to the individual child's needs. Specific to adults, the transition may include visits to the community residence before actual transfer.

Additional supports needed for transition: Some additional supports include more funding for community based supports such as targeted case management, comprehensive psychiatric rehabilitation, new medications, supported housing, and supported employment to make these services available to all people who are eligible; more community based mental health services for people with co-existing conditions (i.e. mental health and substance abuse or metal health and developmental disabilities).

- More safe and affordable community housing;

- More public transportation, particularly in non-urban areas of the state; and

- More success in recruiting, hiring, and retraining qualified and competent staff, particularly at the direct client care level.

The Department of Mental Health is currently developing best practices treatment models for these populations at both the inpatient and community-based level.

Ideal process for transitioning individuals with disabilities: The process should be individualized to the person and their specific circumstances based on planning between the person and his or her treating professionals.

How to determine if an individual is capable of living in a non-institutional setting: For persons who are hospitalized and persons in the CPRC Program in the community, treatment planning process involves the following: The quarterly review and the annual reassessment provides for assessing when they are ready for a more integrated community setting and the process by which the transition will be made. In both cases, the assessment process is multidisciplinary. In the hospital it includes reevaluation by a psychiatrist, nurse, and social worker. In the community it involves reevaluation by case management and psychiatry. The treatment plan must be rewritten at least annually or when any substantial changes in the individual's condition or treatment occur, and is updated quarterly. The treatment planning process is multidisciplinary and also includes participation by the person receiving services. Treatment plans commonly address skills that need to be developed to allow a person to move to more integrated settings such as budgeting, activities of daily living, and housekeeping. Treatment plans are always reviewed with the person receiving services and their signature is requested indicating their review. Specific to children, transition may include visits back and forth between the institution and community-based treatment setting according to the individual child's needs. Specific to adults, the transition may include visits to the community residence before actual transfer.

Department of Mental Health, Division of Mental Retardation/ Developmental Disabilities.

Current process for transition from an institutional setting to the community: All persons are assigned a service coordinator from a regional center and all persons have a person centered plan. This plan must address the needs and desires of the individual, including where the person wants to live. If the person wishes to live in the community, the regional center service coordinator will assist in identifying the supports which would be required, and begin work to secure those supports.

Additional supports needed for transition: If a person chooses to leave an institution and move to the community and the person is unable to live in the community and chooses to return to the institution, attempts will first be made to adjust/improve community supports to better meet the person's need. If this is not satisfactory, and the person wants to move back to the institution, the person will be accommodated.

Ideal process for transitioning individuals with disabilities: This is described above.

How determine if an individual is capable of living in a non-institutional setting. A state treatment professional will determine if the person was voluntarily admitted or court ordered to the institution. Treatment professionals will next determine if the person is a danger to himself and/or others. Finally, the treatment professionals will evaluate the person's services and support needs and determine if the needs can be met in the community so that the person's overall health and safety can be maintained. The person may need opportunities to visit other living arrangements in the community in order to determine the person's interest in relocating to the community.

Department of Health, Adult Head Injury Program

Current process for transition from an institutional setting to the community: The Service Coordinator assists in transition from hospitals to nursing homes and from nursing homes to community. The Service Coordinator intervenes by assisting in planning and setting up services. The Department of Health, along with other agencies, provides services. The Service Coordinator finds resources and ways of funding the services. The Missouri Head Injury Advisory Council also provides valuable information to assist in the transition process.

Additional supports needed for transition: Additional provider support close to the individual's home and community, particularly in rural areas, is needed. One example of more provider support would be in the areas of Personal Care Assistants (PCAs). A system of transportation that would be more readily available to clients was also suggested, as well as accessible recreation activities.

Ideal process for transitioning individuals with disabilities: Implementing the Person Centered Approach throughout the process is critical. This would entail speaking with the person and his/her family about what they want. Public funding and natural supports would also have to be available. The Adult Head Injury Program service coordinator's role is to assure that everyone important in the individual's life is working together toward the plan for community inclusion and independence.

How to determine if an individual is capable of living in a non-institutional setting: There is no process in place. However, the Department of Health is developing an assessment tool for the program and the future Traumatic Brain Injury (TBI) waiver.

Department of Social Services, Division of Aging

Current process for transition from an institutional setting to the community: The Division of Aging (DA) case managers meet with the individual and/or their representative to discuss support systems, met and unmet needs, medical considerations, social concerns, activities of daily living, housing, and all other issues involved in community living. The case manager utilizes the DA assessment tool to guide the discussion and identify needs. Multidisciplinary teams may also be utilized to develop the plan of care for a particular individual. This could include institutional staff, family members, or provider agency staff. Ombudsman volunteers, Area Agencies on Aging (AAAs), Centers for Independent Living, Department of Mental Health (DMH), other agencies, and the DA case manager. The team would identify specific services needed. Once a person returns to the community, the DA case manager follows up with the consumer as needed to ensure that the care plan is adequate to meet his or her needs.

Additional supports needed for transition: In many cases an individual needs 24 hour oversight. DA services are not, by design, intended to be the only support system available and every effort is made to coordinate with other agencies and resources. Other major areas of concern include the need for affordable/accessible housing, assisted transportation, respite care, direct support or caregivers, and the funding necessary to make the transition back to community living. The ability to provide assistance in each of these areas is linked to the requisite corollary fiscal support.

Ideal process for transitioning individuals with disabilities: Discharge planners/social workers within nursing facilities are in an ideal position to identify and work with person who wishes to return to a community setting. Designation of the lead agency would be imperative in situations that involve multiple agency programs. Establishing a multidisciplinary team to identify needs and potential resources would also be necessary components. The plan of care would be developed with input from all parties concerned, especially the consumer, family members, physician, provider agency, and other significant persons or agencies. Professional staff support would be provided to those customers who choose to self-direct their care, and the designated case manager would be given responsibility for the coordination of services, communication between all parties involved, and any necessary follow up activities. Any subsequent problems or concerns would be resolved with input from the team.

How to determine if an individual is capable of living in a non-institutional setting: The individual's self-assessment and choice is a critical part of this process. DA has a comprehensive assessment process to determine an individual's functional limitations, living arrangements, support systems, medical issues, financial resources, and the risk of abuse, neglect, or exploitation. The assessment is utilized to develop a service plan in line with consumer choice which addresses the individual's unmet needs. DA case managers consult with agency nurses, supervisory staff, provider staff, and other professionals as necessary to assure the consumer's safety and welfare in a community setting.

Department of Social Services, Rehabilitation Services for the Blind

Current process for transition from an institutional setting to the community: The Rehabilitation Services for the Blind (RSB) would upon referral provide eligible blind/visually impaired individuals with rehabilitation teaching services, including Braille, travel, cooking, skills of daily living, etc. as needed to live independently.

Additional supports needed for transition: Blind/visually impaired seniors may need a comprehensive array of service to return home.

Ideal process for transitioning individuals with disabilities: The "Ideal Process" would depend on the individual and their needs.

How determine if an individual is capable of living in a non-institutional setting: RSB staff does not typically make this kind decision. Information is offered on the independent living skill level of an individual.

Identification of Barriers and Recommendations from the Olmstead Committees:

Following are barriers and related recommendations from the Olmstead Committees related to transition from institutions to community living.

- **Barriers:**People who are in nursing homes have to sue their SSI checks to pay for nursing home care at the first of the month. Thus, people never have money to move into

the community and cover transitional costs such as rent deposits, utilities, etc. One months SSI payment is probably not enough to cover all costs.

Recommendations:

a. Develop and fund for Olmstead Transition Funds to be administered by the Governor's Council on Disability.

b. The state should look for unique ways in which to fund some of the needs of people with disabilities who transition from institutions to community settings, including but not limited to, bringing in private sector for donations of furniture or adaptive equipment, using public agencies to assist with utility deposits and rental deposits, using interest free loans.

c. Lobby for a discretionary fund to cover emergencies and unique needs to help avoid institutional placement of any individual.

- **Barriers:** Schools are not involved in helping students with disabilities to get into community services and community life. Under IDEA, schools are mandated to provide transition services to children who reach age 14 or 16. Special education students are supposed to have a transition plan included in their Individual Education Plan (IEP). Sometimes this is referred to as transition from school to work, but it also includes transitioning from school to "independent living." The Department of Elementary and Secondary Education (DESE) had a grant to cover transition services, but the grant funding is running out. In Missouri SB321 was passed by the 87th General Assembly, but it was never funded.

  Recommendations:

  a. Local school districts must be mandated to meet the conditions of the Olmstead decision.

  b. Assure that Missouri SB321 (Transition Advisory Council) is fully funded.

- **Barriers:** There are many aspects of transition from an institutional setting to a community setting that require individualized attention.

  Recommendations: A person-centered planning process should be conducted with each person who transitions from the institution to a community setting. This process should follow the person into the community to assure that the supports needed in the community are available.

Timelines & Responsible Parties:

The Commission has reviewed the issue of waiting list movement for people with disabilities who are eligible for community-based treatment. It is critical that proper timeframes for movement through these processes be developed, but premature to develop before the processes are finalized. The Commission recommends that each agency develop and implement these timelines after assessing their waiting lists, their resources, and assessment processes. We recommend that as part of the Commission's on-going charge, the Commission review these timelines for appropriateness and true movement. This review should be completed and reported on by June 30, 2001.

The following table summarizes recommendations, identifies agency(ies) responsible for planning and initiating activities to realize each recommendation, and identifies the calendar year in which the results will be achieved: The code for state agencies is:

- DESE- Department of Elementary and Secondary Education
- DVR- Division of Vocational Rehabilitation
- DMH- Department of Mental Health
- ADA- Division of Alcohol and Drug Abuse
- CPS- Division of Comprehensive Psychiatric Services
- MRDD- Division of Mental Retardation/Developmental Disabilities
- DOH- Department of Health
- AHIP- Adult Head Injury Program
- DSS- Department of Social Services
- DA- Division of Aging
- DMS- Division of Medical Services
- RSB- Rehabilitation Services for the Blind
- MATC – Missouri Assistive Technology Council
- MHDC – Missouri Housing Development Corporation
- GCD – Governor's Council on Disability
- MPC – Missouri Planning Council for Developmental Disabilities

Recommendations:

1a. Develop and fund Olmstead Transition Fund to be administered by Governor's Council on Disability.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Governor's Council on Disability will develop a proposal.	GCD		X

1b. The state should look for unique ways in which to fund some of the needs of people with disabilities who transition from institutions to community settings, including but not limited to, bringing in private sector for donations of furniture or adaptive equipment, using public agencies to assist with utility deposits and rental deposits, using interest free loans.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Division of Comprehensive Psychiatric Services and its contract providers will continue to seek natural supports such as private donations in planning with consumers.	DMH-CPS	FY01	

1c. Lobby for a discretionary fund to cover emergencies and unique needs to help avoid institutional placement of any individual.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Governor's Council on Disability	GCD		X
Missouri Planning Council on Developmental Disabilities	MPC		X

2. Recommend that Missouri SB321 (Transition Advisory Council) is fully funded.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Agencies will participate in the development of an interagency agreement that defines transition services under IDEA, and clarifies	DESE-DVR	X	

responsibility among all departments and agencies in assisting young people to access necessary services and supports so that they can live and/or work in the community as independently as possible after they leave school.	DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DMS DSS-RSB		

3. A person-centered planning process should be conducted with each person that transitions from the institution to a community setting. This process should follow the person into the community to assure that the supports needed in the community are available.

Activities	Responsible Agency(ies)	Year Achieved FY01	FY02
Division of Comprehensive Psychiatric Services and its contract providers will continue to follow a person-centered planning process for each person transitioning from an institution to a community setting.	DMH-CPS	X	X
DMRDD will use the person centered planning process for persons who will leave state operated habilitation centers in order to best plan for the individual's support needs in the community.	DMH-MRDD	X	X
Assure that individuals eligible for the Adult Head Injury Program will have a person-centered philosophy as the focal point of their rehabilitation program.	DOH-AHIP	X	
DA will enhance their case management process	DSS-DA	X	

Budget Action, Federal Action, and Statute Changes.

Needed Budget Action:

- Olmstead Transition Fund.
- Recommend Missouri SB321 Transition Advisory Council be funded.

Federal Action: None required.

Statute Changes: None required.

Activity No. 6: Recommend any modifications or changes that may be needed to improve existing home and community-based services and consumer-directed care programs.

Activity No. 7: Recommend any potential means of expanding home and community-based services or consumer-directed care programs.

Recommended modifications, changes, and expansion of community-based services or consumer directed care programs are addressed within the following seven areas:

1. Direct Care/Attendant Care
2. Housing
3. Inter-Agency Coordination and Agreements
4. Medicaid Services
5. Funding Mechanisms
6. Transportation
7. Employment

For each of these seven areas a summary is included that provides:

1. Background Information
2. A Summary of Related Public Comments
3. Related State Agency Information
4. Identification of Barriers and Recommendations by Olmstead Committees
5. Timelines and Responsible Parties to Implement Recommendations
6. Needed Budget Action, Federal Action, or Statute Changes

Direct Care/Attendant Care

Background Information: In order to live in the community, many individuals with disabilities require the assistance of a Personal Care Assistant or attendant to assist them in meeting a wide variety of personal care and daily living needs. In addition, the availability of other direct care supports such as homemaker, home health care, and other services are required by others to support their community living. The Direct Care/Attendant Care Sub-Committee of the Commission has focused exclusively on this topic and more specifically explored issues related to wages, turnover, credentialing, training, provider choice, regulations, background checks, and budget issues related to direct support professionals (DSP).

Summary of Related Public Comments: A wide range of comments were received on this issue during the public hearings and covered areas related to the lack of availability of assistants, the large number of staff vacancies, high turnover, low pay, lack of benefit packages, direct payment to families, licensing, training, restricted use, use of fiscal intermediaries, and family care. Following are representative comments received during the hearings:

> *Personal Care assistant is of primary concern. I have to have that because I do have to work to support him and I ... and I want to be able to give Dillon the things that he needs in our home to stay in our home.*

There were multiple issues and concerns related to Personal Care Assistants. In order to live in the community, many individuals with disabilities require the assistance of a Personal Care Assistant. One of the subcommittees of the Commission focused on the issue of Personal Care Assistants. Someone at each of the public hearings addressed this topic. Since there are many different aspects to the subject of Personal Care Assistants, this topic is subdivided into some of the issues that people with disabilities face.

Availability: The resounding consensus echoed repeatedly was that it was difficult to find Personal Care Assistants. *Our biggest problem is home care, trying to get the care for me. That is the hardest thing to keep. It is like a revolving door. We don't know who is coming in one day after the other* (Columbia).

Staff Vacancies: Many providers described that they could not find people to fill vacancies as Personal Care Assistants. This had caused, for one agency, overtime *in excess of 13 thousand dollars a month* (Kansas City).

High Turnover: The turnover rate for Personal Care Assistants is approximately 30% in a system that employs 3800 direct care workers. One provider stressed this issue with a case study. *He has to have 24 hour care so that means x number of people per day that are needed. When you have five or six people and they work two months, then leave, someone else comes along.* The provider described how *you spend all your time trying to put out little fires instead of trying to help the individual.* One provider states that you typically replace these employees about three times each year.

Low Pay: One reason for the turnover in Personal Care Assistants is the low pay. The average rate of pay is between $8.50 and $10 per hour. One participant in Kirksville stated *the rate of reimbursement has got to be looked at. What these aides do is phenomenal.* A Kansas City consumer felt that the pay should be *more competitive with other service industries in the state. If not, we will eventually be offering less service than we are now* (Kansas City). In Springfield one speaker noted *When the average caregiver can go to Wal-Mart and receive wages and benefits, it doesn't do much for keeping a compassionate caregiver in that profession where they are needed most.* It was recommended that the pay for Personal Care Assistants be raised $2 an hour immediately. (Kansas City).

One Kansas City provider noted that *Provider contract increases for direct care staff raises over the last 12 years have averaged three-fourths of one percent while the cost of doing business in the community has increased four percent a year.*

Lack of Benefit Package: Many providers discussed the lack of a benefit package (health and dental insurance, life insurance, paid time off, 401K) as a detriment to retaining Personal Care Assistants. As one Personal Care Assistant described *The reason why a lot of them ain't sticking around theirselves - no insurance* (Kirksville). A consumer in Columbia echoed this *It's hard to keep the attendant because they want to have benefits like if they had to go to the dentist or something like that, you need to have the money to have to go to the dentist* (Columbia). A St. Louis consumer also described this *How do you keep them? Because they don't get gas mileage. They don't get benefits, health benefits. They don't want to stay.*

Direct Payment to Families: One suggestion in Kirksville was that families receive payment for the services that they provide to their family member. A woman in Columbia also asked that her *husband to be*

qualified as a caregiver because he has been put in a situation where there was nobody to come and take care of me. He had to do it. (Columbia).

Licensing: Part of the problem that exists is related to licensing. What is the role of the nurse and what is the role of the Personal Care Assistant. There are many turf battles here. There are many tasks that only a nurse can do. *If you are paying them [personal care assistant[they cannot pass medications. They cannot set up medications. WE can't open a medication container. WE can allow them to look at the medication. WE can put the medication cup in their hand and assist them with that, but they can't take the pills out of the pill bottle and put them in a cup. It is illegal for anybody unlicensed to do that. I just want to know how that will be directed through more independent programs than through registered nurse monitored programs?*

The state requires that as soon as reimbursement in involved, then the person must have a certain level of knowledge. As one speaker stated, *who is going to be responsible if a client has a skin breakdown and is never told because the aide is not knowledgeable enough to inform them of that? Who is going to be responsible if that aide overmedicates.*

Training: Training, or the lack of it, for Personal Care Assistants was an issue for some consumers and providers. One speaker who was a PCA reported that *PCAs do not have the correct training to be doing the type of work that they are doing. They have people in wheelchairs that are totally disabled that need special types of lifting abilities. These people are not trained to do these kinds of things* (Columbia),

Restricted Use: In many cases (such as the Division of Aging funding), a Personal Care Assistant can only be used in the home and cannot be used in the community. *The personal care part is very restricted for me. I need this support wherever I go. Division of Aging says this must be served at home* (Columbia).

*Abuse:*Some participants at the hearings noted that they had experienced abuse at the hands of Personal Care Assistants. *I have been stolen from, verbally abused, mistreated in ways you can'' begin to imagine. I cannot believe that these agencies that et paid by the government can get by with treating sick, disabled, and elderly human beings like dogs and not getting a warning notice or reprimand* (St. Louis). For another St. Louis consumer *When I had a homemaker come out to my home, stole some checks, took the checks and the ID card to the bank and tried to cash it.*

Fiscal Intermediary: One Kansas City parent discussed the Family Directed Support Program and *one of the issues that came to the forefront was the idea of having to involve a fiscal intermediary in order to pay for the care provider. It was found that using available intermediaries that were available appeared to me to be a very costly undertaking. The amount that the FI's were charging seemed excessive in my opinion* (St. Louis).

One St. Louis resident spoke about the flexibility that they had in hiring Personal Care Assistant. *What I want to let you know is that the Department of Mental Health funding allows us to use a fiscal agent. And that has allowed us to pay our worker more, to hire the worker ourselves, and to provide individualized training to that worker concerning Ron's needs. The Division of Aging funding for a personal care assistant does not.*

Family Care: Some speakers posed the proposition that families be paid the personal care assistant fees to care for their family member with a disability. The reasons for this were similar to that of a woman from Springfield: *But I've found with the problem of having people come in the home, I was spending about as much time telling people how to take care of him, showing them how to take care of them. By the time I got through the training and go they last about a week and then they didn't want to do anymore. They weren't getting paid enough and it's hard work and I understood that I was having to go through the same thing again.* She described that she could get paid to care for a person with a disability who lived next door, but not her own son.

Consumer-Driven: Some consumers highlighted the need for Personal Care Assistants that were consumer driven. *I believe it would be in the best interest of the patients everywhere if we could get funding for the HB 1111 program or Olmstead program that lets the patient hire the caregiver they want. Not only is it in the best interest of the patient, but it to work that care about their job.*

In St. Louis many consumers described self-directed Personal Care Assistant services. *I have aids that come to me. They have no training. I trained them. I know what they can do. They know what they can do. They can go anywhere now and work for a quadriplegic. When they came, they didn't know what a quadriplegic was.*

State Agency Information: The following are representative comments received from state agencies regarding expanding or improving home and community-based services and consumer-directed care programs relative the issue of personal care:

- The Division of MRDD
  1. *"Increase the number of participants in and the flexibility of the PD Waiver"*
  2. *"Increase access to nursing services for adults who choose to live at home or in community-based settings, e.g. providing a limited amount of private duty nursing. In the Home Health Program, consider allowing for exception to the 100-visit limit, on a prior-authorized basis"*
  3. *"Consider changes to the Nurse Practice Act that present barriers to obtaining nursing care in more integrated settings"*
  4. *"Expand flexibility of state plan personal care services to the maximum extent allowed by HCFA. This would include allowing the service to be provided outside the home and allowing consumers and families to hire their own workers"*
  5. *"Increase direct care worker wages"*

- Division of Vocational Rehabilitation

1. *Eliminate the following barriers –*
   a. *"Consumer Directed Medicaid State Plan is not available to consumers with cognitive impairments",*
   b. *"Medicaid State Plan is limited to a number of hours available per consumer per month", that is based on current unit rate and the monthly average nursing home rate.*
   c. *"Some consumers are Medicaid eligible in the nursing home but are not Medicaid eligible once they leave the facility",*
   d. *"Difficult to maintain a pool of available personal care attendants due to a low unemployment rate",*
   e. *"Maximum unit rate established for personal attendant care is inadequate in some areas of the state with a high cost of living",*
   f. *"Lack of affordable medical benefits for personal care attendants"*
2. *"Increase pay and benefits for attendants"*
3. *"Increase training and certification options for attendants"*

- Division of Comprehensive Psychiatric Services
  1. *"More success in recruiting, hiring, and retaining qualified and competent staff, particularly at the direct client care level"*

Identification of Barriers and Recommendations by Olmstead Committees: Following are barriers and related recommendations from the Gaps and Barriers/Systems Change Sub-Committee related to personal care:

1. **Barrier:** *"Division of Aging agency-controlled personal care services are often no available all the time when people need them, for example at night or on weekends. Advanced personal care services are not available in all parts of the state"*
   Recommendation: *"DOA should require home health agencies to have attendants available to work any day of the week at any time the person needs it"*

2. **Barrier:** ***"****There are not enough providers available for community supports. If there were more consumer-control options available, people could hire their neighbor or friend – it wouldn't matter if the provider agency didn't have enough staff"*

Recommendation:

a. "Increase consumer-controlled options. Recruit and train people with disabilities to be attendants"
b. Provide training to people with disabilities about how to coordinate, negotiate, purchase, direct, hire, fire, attendants, identify quality indicators in DSPs or support services provider agencies. Training to be provided by self-advocacy organizations such as Missouri People First and Independent Living Centers.

3. **Barrier:** ***"****Another reason for difficulty in finding attendants is reimbursement rates are too low to pay decent wages to attract quality attendants. In 1990 in Massachusetts, reimbursement rates for personal care are $20/hr."*

   Recommendation: *"Increase wage of attendants and find way to provide statewide health insurance and other benefits"*

4. **Barrier:** There exists a crisis in the availability of competent direct support professionals. The current labor pool is under paid, receives few benefits, is receive little training and support. This results in very high turnover and a shortage of qualified direct support professionals.

   Recommendations:

   a. Consistent with the Caregiver Commission recommendation for direct workers, $2 per hour per year for the next three years, for a total of $6 per hour over the three years to increase direct workers/attendant workers wages and/or provide benefits. This recommendation is also consistent with previous appropriations.

   b. Core Competency based training for DSP that leads to credentialing for up to 3 years with CEU's required. An option to test out of training hours should be included. Individual training would be provided by the consumer specialized to their needs. Possibly make the credentialing voluntary, but linked to higher pay and benefits.

   c. Consistent with recommendation number 2, there needs to be the development of a skills standard such as the "Community Support Skills Standards" a National Skill Standards for Entry Level Roles in the Human Service Industry developed by Human Resources Research Institute on 1995. HSRI was concerned with the development of competent "community-based support human service practitioner (CSHSP). One of the critical pieces is that personal assistants, DSP's, etc., should be trained to meet the needs and preferences of the person with a disability.

   d. There needs to be clarification about the ability of personal attendants to assist with tasks such as medications, colostomies, and wound care under the Nurse Practices Act.

   e. A background screening must be completed on all DSP in order to provide services. Currently the caregiver background screening form can be submitted to the Missouri State Highway Patrol and for a fee of $5 you will receive within 15 days information from the entire list checked on the background screening form. The list includes the following: State criminal background checks, conducted by the Missouri State Highway Patrol; Child abuse/neglect records, maintained by the Division of Family Services; Family Foster Care Licensing records, maintained by the Division of Family Services; The Employee Disqualification List, maintained by the Division of Aging; The Disqualified Registry, maintained by the Department of Mental Health; Child Day Care licensing records, maintained by the Department of Health. It is imperative that a common database of disqualified, abusive/neglectful people be developed so that people with disabilities, their families, and Missouri citizens can be confident that people with disabilities are not being put in harms way due to poor record keeping of people who have a history of abuse and neglect.

Timelines and Responsible Parties to Implement Recommendations: The following table summarizes recommendations, identifies agency(ies) responsible for planning and initiating activities to realize each recommendation, and identifies the calendar year in which the results will be achieved:

Recommendations:

1. "DOA should require in home agencies to have attendants available to work any day of the week at any time the person needs it."

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Enhance existing requirement for 24/7 care	DSS-DS	X	
Request increased funding to pay shift differentials for different shifts	DSS-DA	X	
Request increased funding to pay shift differentials for different shifts	DSS-DMS	X	

2a. "Increase consumer-controlled options. Recruit and train people with disabilities to be attendants."

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Collaboration to expand consumer controlled options	DSS-DMS DSS-DS	X	
Division of Comprehensive Psychiatric Services is developing a position with the Community Psychiatric Rehabilitation Program for consumers with appropriate training to provide direct serivces to other consumers as case management assistants. Will expand number in FY 02.	DMH-CPS	X	
DMRDD will provide information and technical assistance for regional center service coordinators on consumer directed services.	DMRDD	X	

2b. Provide training to people with disabilities about how to coordinate, negotiate, purchase, direct, hire, fire, attendants, identify quality indicators in DSPs or support service provider agencies. Training to be provided by self-advocacy organizations such as Missouri People First and Independent Living Centers.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

3. "Increase wage of attendants and find ways to provide statewide health insurance and other benefits."

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Request funding increase	DSS-DMS	X	
DMRDD's FY'2002 budget includes a request for an additional $2 per hour for DSPs (and supervisors) for wages and/or benefits.	DMRDD	X	
DMRDD's FY'2002 budget includes a request for a 3% COLA for all providers.	DMRDD	X	

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4a. Consistent with the Caregiver Commission recommendation for direct workers, $2 per hour per year for the next three years, for a total of $6 per hour over the three years, to increase direct workers/attendant workers wages and/or provide benefits. This recommendation is also consistent with previous appropriations.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Request funding increase	DSS-DMS DESE-DVR	X	
DMRDD's FY 2002 budget includes a request for an additional $2 per hour for DSPs (and supervisors) for wages	DMRDD	X	
DMRDD's FY 2002 budget includes a request for a 3% COLA for all providers	DMRDD	X	

4b. Core Competency based training for DSP that leads to credentialing for up to 3 years with CEU's required. An option to test out of training hours should be included. Individual training would be provided by the consumer specialized to their needs. Possibly make the credentialing voluntary, but linked to higher pay and benefits.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Request Vocational Rehabilitation rule change	DESE-DVR		

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4c. Consistent with recommendation number 2, there needs to be the development of a skill standard such as the "Community Support Skills Standards" a National Skill Standards for Entry Level Roles in the Human Service Industry developed by Human Resources Research Institute on 1995. HSRI was concerned with the development of competent "community-based support human service practitioner (DSHSP). One of the critical pieces is that personal assistants, DSP's, etc., should be trained to meet the needs and preferences of the person with a disability.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Request Vocational Rehabilitation rule change	DESE-DVR		
Will assure that state material regarding appeal process was provided to clients and documented in the client's medical record.	DOH		

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4d. There needs to be clarification about the ability of personal attendants to assist with tasks such as medications, colostomies, and wound care under the Nurse Practices Act.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Board of Nursing clarification		X	

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4e. A background screening must be completed on all DSP in order to provide services. Currently the caregiver background screening form can be submitted to the Missouri State Highway Patrol and for a fee of $5 you will receive within 15 days information from the entire list checked on the background screening form. The list includes the following: State criminal background checks, conducted by the Missouri State Highway Patrol; Child abuse/neglect records, maintained by the Division of Family Services; Family Foster Care Licensing records, maintained by the Division of Family Services; The Employee Disqualification List, maintained by the Division of Aging; The Disqualified Registry, maintained by the Department of Mental Health; Child Day Care licensing records, maintained by the Department of Health. It is imperative that a common database of disqualified, abusive/neglectful people be developed so that people with disabilities, their families, and Missouri citizens can be confident that people with disabilities are not being put in harms way due to poor record keeping of people who have a history of abuse and neglect.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Agencies will work with other state agencies to determine if a common database of disqualified, abusive/neglectful people can be developed.	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSS		X

Budget Items Requested for Next Year Related to Direct Care/ Attendant Care

Needed Budget Action:

Department of Social Services – Division of Medical Services

- Funding for rate changes to pay shift differentials
- Funding for rate changes for wage increases

Department of Mental Health: Comprehensive Psychiatric Services
FY 02 Budget Item –
$601,490 to provide 24 new case manager assistants.

Department of Mental Health, Division of Mental Retardation/Developmental Disabilities
FY'2002 Budget Request
$2 per hour increase for direct care staff & immediate supervisors for salary and/or fringe benefits $50,789,060
FED $30,950,399 GR $19,839,207
FY'2002 Budget Request – DMRDD
3% Provider Cost of Living $ 4,907,345
FED $439,162 GR $4,468,183

Federal Action:

Statute Changes:

- Possible change of Nurse Practice Act – Needs clarification first

Housing

Background Information: One of the primary requirements for anyone transitioning to the community is adequate housing. Individuals with disabilities need to have a range of living options available to them that are of high quality, accessible and affordable.

Summary of Related Public Comments: Comments received on this issue during the public hearings covered issues such as lack of affordable housing, lack of accessible housing, lack of accessible transportation to available housing, and lack of low income mortgage assistance programs. Following are representative comments received during the hearings:

> *At that time the only other option was a nursing home so he lived in a nursing home for a couple of months and he found that wasn't good at all. He wanted to come home right away so he came back home. I had him again for about six years and then I worked with... and we built an apartment complex here in Springfield ... and it had like eight apartments and we would do like home health care for people that lived there, semi-independently. It worked out real well for everybody except my son...because he does require almost total care* (Springfield).

One of the first requirements for living in the community is adequate housing. There must be adequate housing in the community before the individual can transition. Many challenges were described in the hearings. Illustrative of these are:

In Kirksville, a young gentleman described his movement from Fulton State Hospital to an RCF to independent living. The difficulty that he was encountering was that they often closed the facility without giving him another option as to where to turn.

The same issues were raised in Kansas City *availability of quality, accessible and affordable housing within the communities of the individual's choice* (Kansas City). In Kansas City one person stated that *there isn't enough housing.* In Kansas City, it was felt that more *low income housing options should include assisting people to rent or purchase an apartment or a house and live with live-in paid roommates. Assisting people to rent or purchase a house and live with nonpaid roommates with a reduction in rent, utilities for the roommate in exchange for some support and additional staff support.* They suggested *Section 8 which can be used to move people from group homes into an apartment should be used more. Helping people tap into homeownership through low income mortgage programs is necessary. Developing close working relationships with bankers would be essential to facilitating this process* (Kansas City).

In Kansas City, some speakers described the lack of housing for persons with mental illness who end up in the corrections systems. *The only services that they get are being incarcerated* (Kansas City). It was reported that *in Jackson County the numbers vary from 15 to 5- percent of the population in our Jackson County detention Center are persons with mental illness.*

This same issue of adequate, affordable housing came up in the Cape Girardeau public hearings. It was noted that *the people that we have in nursing homes right now who want out, they want to stay in like for*

example Farmington, but the cost of living in Farmington is too expensive and there's not very many affordable accessible apartments available. Not only should housing be affordable and adequate, but for many consumers, it should *be on an accessible transportation route.*

State Agency Information: The following are representative comments received from state agencies regarding barriers and recommendations to expanding or improving home and community-based services and consumer-directed care programs relative to the issue of housing:

- Division on Aging
  1. *"Potential enhancements could include expansion of the Aged and Disabled Waiver at some point to provide additional services such as personal emergency response systems or minor home modifications"*

- Division of MRDD
  1. *"Expand state plan services to include home modifications so homes can be accessible (ramps, doorways widened etc.)*
  2. *Barriers identified included:*
     a. *"Locating accessible, safe, affordable housing"*
     b. *"Locating housing in the community (town) where the person wants to live"*
     c. *"Matching the person to potential persons with whom they could share a house/apt."*

- Division of Vocational Rehabilitation
  1. *Address the barrier of "Lack of affordable, accessible housing*

- Division of Comprehensive Psychiatric Services
  1. *"More safe and affordable community housing"*

Identification of Barriers and Recommendations by Olmstead Committees: Following are barriers and related recommendations from the Gaps and Barriers/Systems Change Sub-Committee related to housing:

1. **Barrier:** Affordable, accessible housing is not available. People cannot move into the community if there is nowhere to live.
   Recommendation: Find incentives to increase enforcement of Fair Housing Amendments. Work with HUD to increase scattered site accessible housing. All available resources, such as CDBGs, HUD set asides and HOYO shall be used.

Following are barriers and related recommendations from the Housing Sub-Committee related to housing:

1. **Barrier:** There are individuals in institutions or whom are at risk of placement in an institutional setting who may qualify for housing assistance, but who are not informed of available housing options or assistance. Accurate, up-to-date information is not always readily available.

Recommendations:

a. A workable system must be developed to insure that individuals who need immediate, and accurate information about the availability of accessible affordable housing in a community are able to obtain it, including the individual with the disability, family members, and case managers in agencies such as the Division of Mental Retardation/Developmental Disabilities, the Division of Aging, and community mental health centers.

b. The Missouri Department of Economic Development should establish a "People with Disabilities" web page within its "Housing and Community" web page as a resource for persons with disabilities and their families, along the lines of the Federal Department of Housing and Urban Development's "Home and Community" web page at a national level.

2. **Barrier:** There is a shortage of accessible affordable housing options for persons with disabilities.

Recommendations:

a. Increase the use in Missouri of Section 811 (supportive housing for persons with disabilities) for both:
   - ♦ grants to nonprofits to develop accessible rental housing.
   - ♦ the Mainstream Program - Section 8 vouchers and certificates for persons with disabilities.

b. Explore how the newly available option of using the Section 8 program for home ownership can be used to expand options for persons with disabilities in Missouri.
c. Increase the use in Missouri of Section 202 (supportive housing for persons who are elderly).
d. Explore options to expand use of Medicaid dollars for affordable accessible housing beyond what is currently available in Medicaid waiver programs.
e. Explore use of a portion of Missouri's tobacco settlement funds to expand affordable, accessible housing.
f. Explore a Housing Disabled Access Tax Credit to assist persons with disabilities or family members with out-of-pocket expenses for housing access modifications.
g. Explore a tax credit for builders of homes with certain accessibility features to expand the stock of available accessible housing.
h. Explore a grant program for urgently needed housing access modifications (Emergency assistance/start up dollars).
i. Explore a "visitability" law similar to that in Texas to require that entities that are awarded state or federal funding assistance to construct single family affordable housing must construct the housing with certain key accessibility features.
j. Include housing specialists to work on Olmstead Implementation Plan.
k. Geographically adjust housing dollars that follow persons into the community.
l. Increase the availability of scattered site accessible housing.
m. Change parameters of state and local service dollars to include housing.
n. Explore inclusion of accessibility related provisions in the recommendations of the Governor's Commission for the Review & Formulation of Building Code Implementation.
o. Enhance opportunities for public/private partnerships to improve availability of affordable accessible housing.
p. Establish, market, and provide consumer assistance for the new low-interest loan program for assistive technology including housing access modifications.
q. Encourage the use of "universal design" principles for both new housing construction and for housing rehabilitation.
r. The Certificate of Need (CON) program is a deterrent for current quality care providers to increase beds (Residential Care Providers only). The CON process should be revisited.
s. Increase the revenue in the Housing Trust Fund and the usage of the Fund. These dollars could then be used for individuals leaving an institution to return to the community for move-in assistance such as utility and phone deposits, and initial needs such as linens and kitchen equipment.
t. Contact communities with Consolidated Housing Plans to encourage the use of the Universal Design concept and prioritize housing for individuals with disabilities.

3. Barrier: The Community Development Block Grant (CDBG) Program is one of the few resources for increasing affordable accessible housing in communities. In Missouri, CDBG funds are rarely used for projects addressing home accessibility.
Recommendations: Explore with the Missouri Department of Economic Development methods for encouraging and awarding funds to counties and municipalities for projects addressing home accessibility needs.

Timelines and Responsible Parties to Implement Recommendations: The following table summarizes recommendations, identifies agency(ies) responsible for planning and initiating activities to realize each recommendation, and identifies the calendar year in which the results will be achieved:

Recommendations:

1a. A workable system must be developed to insure that individuals who need immediate, and accurate information about the availability of accessible affordable housing in a community are able to obtain it, including the individual with the disability, family members, and case managers in agencies such as the Division of Mental Retardation/Developmental Disabilities, the Division of Aging, and community mental health centers.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Strengthen DMH Housing Unit to share information and activities with other agencies	DMH	X	
Division of Comprehensive Psychiatric Services will participate in interagency efforts to assure this recommendation. CPS will also request funding in the FY02 Budget to support 213 consumers in moving from congregate to independent living situations - $1,400,400.	DMH-CPS		X
DMRDD service coordinators will be provided information on accessing and using the Housing and Community web-page for persons with disabilities when the web-page is developed by the Dept. of Economic Development.	DMRDD		X

1b. The Missouri Department of Economic Development should establish a "People with disabilities" web page within its "Housing and Community" web page as a resource for persons with disabilities and their families, along the lines of the Federal Department of Housing and Urban Development's "Home and Community" web page at a national level.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

2a(1). Increase the use in Missouri of Section 811 (supportive housing for persons with disabilities) for: (1) grants to nonprofits to develop accessible rental housing.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
The Division of Comprehensive Psychiatric Services will work with the Department of Mental Health Housing Team to increase use of 811 grants	DMH-CPS		X
The DMH Housing Team will provide information and technical assistance to DMRDD staff and providers on Section 811 rental options for persons with disabilities.	DMH Housing Team	X	

2a(2). Increase the use in Missouri of Section 811 (supportive housing for persons with disabilities) for: (2) the Mainstream Program –Section 8 vouchers and certificates for persons with disabilities.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
The Division of Comprehensive Psychiatric Services will work with	DMH-CPS		X

the Department of Mental Health Housing Team to increase use of 811 vouchers.			
The DMH Housing Team will provide information and technical assistance to DMRDD staff and providers regarding the Mainstream Program	DMH Housing Team	X	

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2b. Explore how the newly available option of using the Section 8 program for home ownership can be used to expand options for persons with disabilities in Missouri.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
The Division of Comprehensive Psychiatric Services will work with the Department of Mental Health Housing Team to participate in an interagency effort to explore Section 8 options	DMH-CPS		X
The DMH Housing Team will provide information and technical assistance to DMRDD staff and providers regarding home ownership options.	DMH Housing Team	X	

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2c. Increase the use in Missouri of Section 202 (supportive housing for persons who are elderly).

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
The Division of Comprehensive Psychiatric Services will work with the Department of Mental Health Housing Team to participate in an interagency effort to increase the use of Section 202	DMH-CPS		X
The DMH Housing Team will provide information and technical assistance to DMRDD staff and providers on Section 202 options.	DMH Housing Team	X	

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2d. Explore options to expand use of Medicaid dollars for affordable accessible housing beyond what is currently available in Medicaid waiver programs.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Federal law currently does not permit Medicaid dollars to be spent for housing	DSS-DMS		
Initiate discussions at the Federal level to provide more flexibility for the definition of room and board	DSS-DMS	X	
Division of Comprehensive Psychiatric Services will work with the Department of Mental Health Housing Team to participate in an interagency effort to expand use of Medicaid dollars	DMH-CPS		X

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2e. Explore use of a portion of Missouri's tobacco settlement funds to expand affordable, accessible housing.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

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2f. Explore a Housing Disabled Access Tax Credit to assist persons with disabilities or family members with out-of-pocket expenses for housing access modifications.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

2g. Explore a tax credit for builders of homes with certain accessibility features to expand the stock of available accessible housing.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

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2h. Explore a grant program for urgently needed housing access modifications (Emergency assistance/start up dollars).

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Apply for Federal Grants	DSS-DMS	X	
Request funding for home modifications under the waivers	DSS-DMS		

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2i. Explore a "visitability" law similar to that in Texas to require that entities that are awarded state or federal funding assistance to construct single family affordable housing must construct the housing with certain key accessibility features.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

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2j. Include housing specialists to work on Olmstead Implementation Plan.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
DMH Housing Team specialists will assist DMRDD staff in implementing the State's Olmstead Plan as it relates to housing issues for people served by DMH.	DMH Housing Team		X

2k. Geographically adjust housing dollars that follow persons into the community.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

2l. Increase the availability of scattered site accessible housing.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
The DMH Housing Team will provide information and technical assistance to DMRDD staff and providers on scattered site accessible housing options.	DMH Housing Team	X	

2m. Change parameters of state and local service dollars to include housing.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

2n. Explore inclusion of accessibility related provisions in the recommendations of the Governor's Commission for the Review & Formulation of Building Code Implementation.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

2o. Enhance opportunities for public/private partnerships to improve availability of affordable accessible housing.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

2p. Establish, market, and provide consumer assistance for the new low-interest loan program for assistive technology including housing access modifications.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
DMRDD will provide service coordinators information and training on the new low-interest loan program for assistive technology including housing access modifications.	DMRDD	X	

2q. Encourage the use of "universal design" principles for both new housing construction and for housing rehabilitation.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

2r. The Certificate of Need (CON) program is a deterrent for current quality care providers to increase beds (Residential Care Providers only). The CON process should be revisited.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

2s. Increase the revenue in the Housing Trust Fund and the usage of the Fund. These dollars could then be used for individuals leaving an institution to return to the community for move-in assistance such as utility and phone deposits, and initial needs such as linens and kitchen equipment.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
DMRDD will provide information and training to service coordinators if a transition fund is established in the Housing Trust Fund.	DMRDD		X

2t. Contact communities with Consolidated Housing Plans to encourage the use of the Universal Design concept and prioritize housing for individuals with disabilities.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

3. Explore with the Missouri Department of Economic Development methods for encouraging and awarding funds to counties and municipalities for projects addressing home accessibility needs.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

Budget Items Requested for Next Year Related to Housing.

Needed Budget Action:

Department of Social Services – Division of Medical Services
- Funding for home modifications under the Home and Community Based Waivers

Department of Mental Health, Division of Comprehensive Psychiatric Services
- FY 02 budget request – Funding to support 213 consumers in moving from congregate to independent living situation $1,400,400.

Department of Mental Health, Division of Mental Retardation/Developmental Disabilities
- FY'2002 Budget Request – DMRDD
  Shelter Plus Care Grant $1,416,384
  FED $708,192 GR $708,192

Federal Action:

- Obtain authority from Health Care Financing Administration to provide or expand home modification services under the Home and Community Based waivers

Statute Changes:

Background Information: Many individuals with significant disabilities living in the community require the services and supports available through a variety of community and state agencies. This maze of services is at times confusing and difficult to navigate by those living in the community with disabilities. In addition, the communication and coordination between agencies providing these services is at times lacking.

Summary of Related Public Comments: There were a number of comments received regarding the need to have a wide range of supports services and resources available in the community. In addition, comments were received that there needs to be a better assessment of what support services currently exist in communities and what resources need to be developed. These points speak to the need for coordination and agreements between agencies who provide community services and supports. (*insert comments from report)*

State Agency Information: The following are representative comments received from state agencies regarding barriers and recommendations to expanding or improving home and community-based services and consumer-directed care programs relative to the issue of inter-agency coordination and agreements:

- Division of Comprehensive Psychiatric Services
  1. *"The process (for transitioning) should be individualized to the person and specific circumstances based through planning between the person and his or her treating professional*

- Traumatic Brain Injury Program
  1. *"The Department of Health is also working on recruiting smaller agencies that have experiences with persons with disabilities, but not necessarily with TBI. In this instance, Service Coordinators do specialized training in these agencies and work closely in a mentoring capacity."*

- Division on Aging
  1. *" DA has partnered with hospitals, clinics and other community sites to base staff in settings that are easily accessible for seniors and persons age 18-59 with disabilities. The Community Outreach Initiative also provides DA with the ability to arrange necessary services in a more timely manner."*

  2. *"DA has partnered with UMC to utilize the Community Connection database for our Shared Care program. Shared Care is a system by which caregivers may access information about programs and services to assist them in caring for a loved one. Community Connection is a comprehensive, web-based directory of providers, resources, social service agencies, and other who provide assistance to caregivers"*

  3. *"Designation of the lead agency (transition planning) would be imperative in situations that involve multiple agency programs. Establishing a multidisciplinary team to identify needs and potential resources would also be a necessary component. The plan of care would be developed with input from all parties concerned, especially the consumer, family members, physician, provider agency, and other significant persons or agencies. Professional staff support would be provided to those customers who choose to self-direct their care, and the designated case manager would be given responsibility for the coordination of services, communication between all parties involved, and any necessary follow up activities. Any subsequent problems or concerns would be resolved with input form the team"*

- Division of MRDD
  1. *"Ongoing training is provided from time to time for staff from central office staff. Most recently, central office arranged a videoconference to improve staff knowledge of state plan personal care services and waiver services authorized by Division of Aging, Vocational Rehabilitation, and Bureau of Special*

Health Care Needs. The training included staff from the Division of medical Services and the Division of Aging. Working to coordinate services with other agencies was stressed."

Identification of Barriers and Recommendations by Olmstead Committees: Following are barriers and related recommendations from the Gaps and Barriers/Systems Change Sub-Committee related to inter-agency coordination and agreements:

Barrier: There is inadequate coordination or collaboration between the various state agencies that work with people with disabilities. For example, an individual with a disability may be getting services form DFS and RSB but there is no communication between the offices or coordination of services.
Recommendations: Action needed to complete the below recommendations includes the development of inter-agency agreements and a budget item for information systems. Involved entities should include DESE, DSS, DMH, and DOH.

a. Data linkages and shared information systems among agencies
b. Plan to determine who is the lead agency/primary service coordinator when multiple agencies are involved with a person. The lead/primary service coordinator should stay in touch with all of the others. There will be an inter-agency coordinating task force that will develop a plan for data linkages and service coordination. Action plan will be developed by July 1, 2001.
c. Service coordinators should know about all services in the "person-centered" plan, not just those that the service coordinator's agency funds. Service coordinators need on-going training.
d. Have a central phone number that individuals can call and get information about community services – perhaps start this as a pilot. July 1, 2001.
e. Have a universal application form for all home and community-based services so that a person or family does not have to go to several different agencies and fill out several forms. April 1, 2001
f. Have a comprehensive chart of what community services are available and what the criteria for each program are. April 1, 2001.

Barrier: Conflict between funding streams. One specific instance is a conflict over what the VA will pay and what DMH will pay for. Regulations say that services available through the VA (physician visits, housing) must be paid by the VA, but there is no funding available through the VA so the person doesn't get the community services they need. This affects 3 or 4 individuals a year in the St. Louis area. **Recommendations:** Allow funding streams to be blended so that an individual could receive services from two or more sources at the same time. Establish an inter-agency mandate that funding streams be blended. An analysis of what regulations and statutes need to be changed to allow that will be done by April 1, 2001.

Timelines and Responsible Parties to Implement Recommendations: The following table summarizes recommendations, identifies agency(ies) responsible for planning and initiating activities to realize each recommendation, and identifies the calendar year in which the results will be achieved:

Recommendations:

1a. Data linkages and shared information systems among agencies.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Division of Comprehensive Psychiatric Services will participate through the Department of Mental Health which operates its information systems.	DMH-CPS DMH-ADA DMH-MRDD DESE-DVR DSS-DA DMH-MRDD DOH-AHIP		X

1b. Plan to determine who is the lead agency/primary service coordinator when multiple agencies are involved with a person. The lead/primary service coordinator should stay in touch with all of the others. There will be an inter-agency coordinating task force that will develop a plan for data linkages and service coordination. Action plan will be developed by July 1, 2001.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Participate in Task Force	DSS-DMS DSS-DA DMH-CPS DMH-ADA DMH MRDD DESE-DVR DOH-AHIP	X	

1c. Service coordinators should know about all services in the "person-centered" plan, not just those that the service coordinator's agency funds. Service coordinators need on-going training.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Agencies will participate in the inter-agency coordinating task force.	DMH-CPS DMH-MRDD DMH-ADA DESE-DVR DOH-AHIP		X
DMRDD, through ongoing information and training, will reinforce the value of service coordinators being knowledgeable of all services in a person centered plan, regardless of payment source.	DMRDD	X	

1d. Have a central phone number that individuals can call and get information about community services – perhaps start this as a pilot July 1, 2001.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Agencies will participate in disseminating 1-800 hotline numbers as designed by the Olmstead Commission	DESE-DVR DMH-ADA DMH-CPS DMH-MRDD DOH-AHIP DSS-DA DSS-DMS DSS-RSS		
	DMRDD	X	

1e. Have a universal application form for all home and community-based services so that a person or family does not have to go to several different agencies and fill out several forms. April 1, 2001.

	Responsible Agency(ies)	Year Achieved 2001	2002
Participate in work group to develop an universal application	DSS-DA DSS-DMS DMH-CPS DMH-ADA DMH-MRDD DOH-AHIP DMH-MRDD DESE-DVR	X	

1f. Have a comprehensive chart of what community services are available and what the criteria for each program are. April 1, 2001.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Participate in an interagency effort to develop the chart and distribute it to appropriate staff.	DSS-DA DSS-DMS DMH-CPS DMH-ADA DESE-DVR DMH-MRDD DOH-AHIP		

2. Allow funding streams to be blended so that an individual could receive services from two or more sources at the same time. Establish an inter-agency mandate that funding streams be blended. An analysis of what regulations and statutes need to be changed to allow that will be done by April 1, 2001.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

Budget Items Requested for Next Year Related to Inter-Agency Coordination and Agreements.

Needed Budget Action:

- 211 system

Department of Mental Health, Division of Mental Retardation/Developmental Disabilities
FY'2002 Budget Request –
128 New Service Coordinators $5,559,558
FED $3,813,504 GR $1,746,054

Federal Action:

Statute Changes:

Medicaid Services

Background Information: Medicaid is a major source of funding for both institutional and community services for individuals with significant disabilities. Unfortunately, there exists many restrictions regarding issues of funding, eligibility, and availability of Medicaid to support individuals with disabilities within community-based settings.

State Agency Information: The following are representative comments received from state agencies regarding barriers and recommendations to expanding or improving home and community-based services and consumer-directed care programs relative to the issue of Medicaid Services:

- Division of Vocational Rehabilitation
  1. *Eliminate the following barriers –*
     a. *Medicaid State Plan is limited to Personal Care Attendant services only*
     b. *"Consumer Directed Medicaid State Plan is not available to consumers with cognitive impairments",*
     c. *"Medicaid State Plan is limited to a number of hours per consumer per month based on the unit rate and average monthly nursing home rate."*
     d. *"Some consumers are Medicaid eligible in the nursing home but are not Medicaid eligible once they leave the facility",*
     e. *"Low income levels for eligibility result in high spend-down levels that consumers must meet before receiving Medicaid services"*
     f. *"Spousal impoverishment rule"*
     g. *"While in a nursing home, no provision though Medicaid to pay for or set aside dollars to pay deposits for housing/rent, utilities, initial furnishing or food"*
     h. *"Age limit of 64 on the consumer-directed Independent Living Waiver program"*
     i. *"Only consumers with a cognitive impairment can appoint a designee for consumer directed care on the IL waiver"*

2. *"Additional capacity could come from expanding and amending the state waiver"*
3. *"If people in nursing homes could set aside some of their social security check while in nursing home care or be provided with some sort of funds when they leave in order to pay for set-up items when it is time to establish community living. Nursing home residents are forced to give up everything when they enter in order to qualify for Medicaid and get trapped in the home because they have no assets when they are ready to leave. Because the Medicaid State Plan only allows up to 6 hours of care per day, those who need more services must access the IL waiver. However there currently is a cap of 470 people on the waiver. So another option for additional capacity for services would be to amend the cap on the state waiver".*

- Division of Comprehensive Psychiatric Services

1. *"Currently Medicaid policy bars from coverage all services provided to adults ages 22 to 64 in Institutions for Mental Disease (IMD). All of the Missouri Division of Psychiatric Services state operated facilities are included in the definition of IMD. If federal Medicaid matching dollars were available in an IMD, it would free up State General Revenue funds to be spent on community based mental health services. The National Association of State Mental Health Program Directors (NASMHPD) has encouraged the Secretary of health and Human Services to initiate and support legislation to repeal the IMD Exclusion."*

2. *"Home and community based Medicaid waivers provide very flexible comprehensive support for people with disabilities living in the community. However, because the IMD Exclusion bars Medicaid reimbursement for services provided in a psychiatric hospital it has operated as a bar to states that want to provide home and community based waiver services to people with mental illness. The NASMHPD has encouraged that the Health Care Financing Administration take steps to expand access to home and community based waivers (191 5c waiver) to serve people with mental illness."*

3. *"There is wide spread agreement that an "institutional bias" inherent in the Medicare program encourages the use of inpatient services and poses a barrier to the delivery of community based services that may be needed to prevent future hospitalization. For people with mental illness, this barrier may mean the difference between recovery in the community and the need for frequent hospital readmissions. The NASMHPD has encouraged the Department of Health and Human Services to support legislation to provide parity for treatment for mental illness under Medicare and continue to support proposals to provide prescription drug coverage under Medicare."*

4. *"The Division of Comprehensive Psychiatric, in cooperation with the rest of the Department of Mental Health, is studying the efficacy of applying for a home and community-based waiver for children with psychiatric and substance treatment needs."*

- Division of MRDD

1. *"Increase the number of participants in and the flexibility of the PD Waiver"*
2. *"Expand flexibility of state plan personal care services to the maximum extent allowed by HCFA. This would include allowing the service to be provided outside the home and allowing consumers and families to hire their own workers"*
3. *"DMS could exercise the TEFRA 134 Option (Katie Beckett) to make more children eligible for state plan (HCY) services"*
4. *"Expand the number of participants who may be served in the Sarah Jian Lopez Waiver"*
5. *"Expand the array of adaptive equipment that can be purchased through the Medicaid state plan (e.g. van lifts)"*
6. *"Expand state plan services t include home modifications so homes can be accessible (ramps, doorways widened, etc.)*

- Division on Aging

1. *"Potential enhancements could include expansion of the Aged and Disabled Waiver at some point to provide additional services such as personal emergency response systems or minor home modifications"*

2. *(Barrier) "An individual may only receive services through one waiver at a time. For example, if a person participates in the Independent Living waiver for persons with developmental disabilities, they cannot access services through the Aged and Disabled waiver programs. The Aged and Disabled waiver program also requires that persons must be at least 63 to access services covered by the waiver. This age limit is determined by the Division of Medical Services and approved by the Health Care Financing Administration."*

- Traumatic Brain Injury Program

  1. *"The Department of Health is working with Medicaid to obtain a TBI waiver for home and community based services."*

Identification of Barriers and Recommendations by Olmstead Committees: Following are barriers and related recommendations from the Gaps and Barriers/Systems Change Sub-Committee related to Medicaid Services:

1. **Barrier:** The asset limits for Medicaid eligibility are too restrictive. Missouri's asset limits is $1,000 for an individual even though federal law allows up to $2,000. As a 209b state, Missouri is not limited to increasing the cash asset limits to just $2,000.
   Recommendations:
   - Increase the resource level to $4000 for an individual. Legislation should be introduced in 2001 session.
   - Expanding the type of assets that are exempt from asset determination. For example, some types of savings accounts, etc. Lobby for HHS proposed rules that increase states' flexibility in determining Medicaid eligibility.

2. **Barrier:** Waiver services can be limited to a specific number of people.
   Recommendations:
   - Waiver services that are allowed by HCFA to be covered by the Medicaid state plan should be worked into the state plan so that they are available to all who need it. Analysis of what can be covered in the state plan and the budget item will be completed by April 1, 2001.
   - To cover services that are not available under the Medicaid state plan and to cover individuals who need more than the cost-neutrality limit, existing waivers should be expanded to serve more people. State agencies that administer waivers will ask for enough funding to cover all individuals and families on waiting lists.
   - If there has to be a waiting list, there should be a monitoring process whereby the state agency must justify why someone is still on a waiting list after 90 days. There should be a standard waiting list format which includes the date someone went on a waiting list and the barriers that are keeping the person on the waiting list (e.g., person is looking for housing, there are no more waiver slots). This is not meant to move someone out of an institution before all the community supports are in place, but is to assure that there is a plan and action is being taken to pull all the supports and services together in a timely manner.
   - To assist adults with head injury, a Medicaid Waiver will be submitted to HCFA.

3. **Barrier:** There must be a comparability of Medicaid services between nursing homes and community-based settings. For example, disposable briefs are paid for in nursing homes but not for those who live in the community. Also, there is no comparability of services between EPSDT and Medicaid for people over 21, e.g., assistive technology.
   Recommendations: Expand Medicaid state plan to include specialized medical supplies and increase number of individuals served on HCBS waivers that provide services not covered in the state plan. See Recommendation under Barrier (2) above.

4. **Barrier:** Medicaid will pay to "hold" a nursing home bed if a resident needs to go into the hospital temporarily, but will not offer the same option to pay for an attendant while an individual needs to be

temporarily out of the home.
Recommendations: Implement the HCFA policy on personal assistance retainer payments.

5. **Barrier:** The assets and/or income of the spouse can either make the individual ineligible or send the individual into a high spend-down. Someone in the nursing home can divide assets and income with spouse to avoid impoverishing the spouse and losing Medicaid eligibility, but person in the community cannot unless they are 63+ on the HCBS elderly waiver. Not all Missouri waivers have this option.
Recommendations: Protect the income of the spouse and allow division of assets in all Missouri HCBS waivers.

6. **Barrier:** When a child, under age 18, is living with his or her parent(s), the parent(s) income and resources are counted in considering if the child is financially eligible for Medicaid. However, if the child enters an institution, the child becomes eligible for Medicaid after being out of the home for 30 days. In Missouri, the option to disregard parent(s) income is only utilized in the Div. of MR/DD Sarah Jian Loez Waiver, which can only serve 200 children.
Recommendations: Missouri should consider exercising the TEFRA 134 Option to allow any child with a disability to continue living at home and become Medicaid eligible by only considering the income and resources of the child and not deeming parental income and resources when determining financial eligibility.

7. **Barrier:** The Medicaid income eligibility is too low. There are many people who do not qualify for Medicaid but cannot afford to pay for health care and attendant services out of pocket. Without the attendant services, they are at risk of institutionalization. There are also many people for whom the spend-down system does not work either because of the high spend-down amount and/or the difficulty of tracking the expenditures. Federal guidelines allow HCBS waiver income guidelines to be set at 300% SSI. Missouri, however, has not chosen that option under the elderly waiver or the Independent Living waiver. Previously, persons on spenddown could have prescriptions filled for a three-month period on the first day or near the first day of their spenddown quarter. This assisted many individuals in meeting their spenddown. Effective Dec. 1, 2000, a restriction has been added to the Medicaid Pharmacy Program that limits prescriptions to a 31-day maximum. Therefore it will take much longer for some individuals to meet their spenddown, and others may no longer be able to meet the quarterly spenddown. An exemption process is being developed to waive this restriction for individuals for whom the loss of Medicaid eligibility would result in a "higher level of care," i.e. institution. However, this requirement still adds to the burden of managing the spenddown process.

   Recommendations:
   - Increase Medicaid income eligibility guideline to 100% of poverty.
   - Increase HCBS waiver income guidelines to 300% SSI.
   - Remove the prescription drug limitation.

8. **Barrier:** Inpatient state-operated mental health facilities are considered Institutions for Mental Disease (IMD), and therefore inpatients are not able to receive community-based Medicaid services to facilitate transition back into the community. Individuals who reside in IMDs are not eligible for Medicaid under federal regulations, and therefore cannot receive services such as community support that might be provided through the Comprehensive Psychiatric Rehabilitation (CPR) Program.
Recommendations: Lobby for HCFA to change its rules and allow Medicaid reimbursement for transition services provided to an individual while they are in an IMD.

9. **Barrier:** Amount and scope of personal assistance services is not adequate to meet every individuals needs. Many people with traumatic brain injury and multiple diagnoses, who fall between the cracks in the current system of community services. The per capita caps on state plan

personal care options harms individuals who need a higher level of care. Not all PAS options can be usable on the job. **Recommendations:**

- Include cognitive, emotional and social supports in definition of PAS.
- Expand waivers so more people who need more hours of PAS than allowed under the cost cap can receive the appropriate level of care.
- Amend state plan to allow all PAS options to be used on the job. Implementation of the TWWIIA Infrastructure grant can make a difference in personal assistance being able to sufficiently support people on the job. Missouri has this opportunity with the recent award of the HCFA Medicaid Infrastructure Grant.
- Support Traumatic Brain Injury Medicaid Waiver.

10. **Barrier:** People with disabilities who return to work often lose access to health care and personal assistance that are necessary to be an effective employee. **Recommendations:** Implement the Medicaid buy-in option authorized by the federal Ticket to Work and Work Incentives Improvement Act. The recent award of the HCFA Medicaid Infrastructure Grant provides the opportunity and resources to plan and develop the Medicaid buy-in program.

Timelines and Responsible Parties to Implement Recommendations: The following table summarizes recommendations, identifies agency(ies) responsible for planning and initiating activities to realize each recommendation, and identifies the calendar year in which the results will be achieved:

Recommendations:

1a. Increase the resource level to $4000 for an individual. Legislation should be introduced in 2001 session.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Fiscal Note (DA Staff and DFS staff also)	DSS-DMS	X	
Implementation	DSS-DFS		

1b. Expanding the type of assets that are exempt from asset determination. For example, some types of savings accounts, etc. Lobby for HHS proposed rules that increase states' flexibility in determining Medicaid eligibility.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

2a. Waiver services that are allowed by HCFA to be covered by the Medicaid state plan should be worked into the state plan so that they are available to all who need it. Analysis of what can be covered in the state plan and the budget item will be completed by April 1, 2001.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Analysis of waiver services	DSS-DMS		
Amend Waiver	VR (with DMS & HCFA		

2b. To cover services that are not available under the Medicaid state plan and to cover individuals who need more than the cost-neutrality limit, existing waivers should be expanded to serve more people. State agencies that administer waivers will ask for enough funding to cover all individuals and families on waiting lists.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Analysis of waiver services	DSS-DMS	X	
DMRDD's FY'2002 budget includes a request for funds to address waiting lists. Many of the service needs of individuals on waiting lists could be provided through the MRDD waiver if adequate GR is appropriated and adequate FED spending authority is approved.	DMRDD	X	

2c. If there has to be a waiting list, there should be a monitoring process whereby the state agency must justify why someone is still on a waiting list after 90 days. There should be a standard waiting list format which includes the date someone went on a waiting list and the barriers that are keeping the person on the waiting list (e.g., person is looking for housing, there are no more waiver slots). This is not meant to move someone out of an institution before all the community supports are in place, but is to assure that there is a plan and action is being taken to pull all the supports and services together in a timely manner.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
DMRDD will include status information for persons who are on waiting lists 90 days or more that explains the delay in obtaining services. DMH is in the process of purchasing a new data system. DMRDD will request that this capability be included in the design of the new system.	DMRDD		X

2d. To assist adults with head injury, a Medicaid Waiver will be submitted to HCFA.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Submit waiver upon receiving budget authority	DSS-DMS	X	
Submit waiver to HCFA	DOH-AHIP	X	

3. Expand Medicaid state plan to include specialized medical supplies and increase number of individuals served on HCBS waivers that provide services not covered in the state plan. (See Recommendation under Barrier 2 above.)

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS	X	

4. Implement the HCFA policy on personal assistance retainer payments.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS	X	

5. Protect the income of the spouse and allow division of assets in all Missouri HCBS waivers.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS		

6. Missouri should consider exercising the TEFRA 134 Option to allow any child with a disability to continue living at home and become Medicaid eligible by only considering the income and resources of the child and not deeming parental income and resources when determining financial eligibility.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS		

7a. Increase Medicaid income eligibility guideline to 100% of poverty.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS	X	

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7b. Increase HCBS waiver income guidelines to 300% SSI. *(Continue to research the 209b and medically needy issue.)*

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS	X	

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7c. Remove the prescription drug limitation.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS	X	

8. Lobby for HCFA to change its rules and allow Medicaid reimbursement for transition services provided to an individual while they are in an IMD.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS	X	
Division of Comprehensive Psychiatric Services and the Department of Mental Health through the National Association of State Mental Health Program Directors will continue to advocate that HCFA and the IMD exclusion.	DMH-CPS	X	

9a. Include cognitive, emotional and social supports in definition of PAS.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS		
Amend state plan with DMS to include cognitive	DESE-DVR DSS-DMS	X	

9b. Expand waivers so more people who need more hours of PAS than allowed under the cost cap can receive the appropriate level of care.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS		

9c. Amend state plan to allow all PAS options to be used on the job. Implementation of the TWWIIA Infrastructure grant can make a difference in personal assistance being able to sufficiently support people on the job. Missouri has this opportunity with the recent award of the HCFA Medicaid Infrastructure Grant.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Explore fiscal impact, develop and submit budget decision items when appropriate	DSS-DMS		

9d. Support Traumatic Brain Injury Medicaid Waiver.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Submit waiver upon receiving budget authority	DSS-DMS DOH-AHIP		

10. Implement the Medicaid buy-in option authorized by the federal Ticket to Work and Work Incentives Improvement Act. The recent award of the HCFA Medicaid Infrastructure Grant provides the opportunity and resources to plan and develop the Medicaid buy-in program.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Budget item submitted	DSS-DMS	X	
Implement if approved	DSS-DMS		X
DMRDD will work with Division of Medical Services staff and other interested agencies and representatives to explore the feasibility of a Medicaid buy-in and potential options for enhancing or adding flexibility to the current state plan personal care service through the TWWIIA Medicaid Infrastructure Grant.	DMH-MRDD	X	

Budget Items Requested for Next Year Related to Medicaid Services.

Needed Budget Action:

Department of Social Services, Division of Medical Services

- Funding for Traumatic Brain Injury Waiver
- Funding for Ticket to Work and Work Incentives Act Medicaid eligibility groups and funding for implementation by DFF-DFS.

Department of Mental Health, Division of Mental Retardation/Developmental Disabilities

FY'2002 Budget Request:

Olmstead Waiting Lists $60,347,097

FED (waiver) $38,711,069 GR $21,636,028

Federal Action:

- Obtain authority for Traumatic Brain Injury waiver services from Health Care Financing Administration
- Division of Comprehensive Psychiatric Services – Federal Action to remove the IMD exclusion.

Statute Changes:

Funding Mechanisms

Background Information: The availability of funding to provide for the services and supports that people with disabilities need to live in the community is at the heart of developing an effective system of community supports. The flexibility, portability, and self-directed nature of the available funding are also key components to the expansion and development of needed funding mechanisms.

Summary of Related Public Comments: Throughout the public hearings the request for more funding predominated. In addition to requests for "more funding" there were numerous requests that funding "follow the individual" and have the flexibility to be used to meet a wide range of individual needs. Following are representative comments received during the hearings:

Funding Following the Person

> *Betty wanted to live on her own, wanted to live in her own place, but have the supports to live on her own. Funding wasn't available. One of the ironies was and still is the funding streams to nursing home placement were free flowing and available for her. That's where she was placed. For eight years Betty lived in a nursing home. I helped move her out so I got to see her clothing were labeled with magic markers with her name on them.* (Columbia)

It was frequently cited that there are funds available for nursing homes, but these funds cannot be used to help people remain in the community. *But the fact was that funding was free flowing for her nursing home placement whereas it wasn't available for the specific support she would have needed in her apartment* (Columbia).

There was a request in Kansas City for funding to be used for whatever the person or family wanted. *Stipends and low interest loans need to be available to all disabled people regardless of age. People should be able to use it for anything they want such as air conditioners, family vacations, home modifications or equipment* (Kansas City).

In St. Louis a parent described a scenarios with their daughter. *The fact that she could qualify for Medicaid in a nursing home, but could not qualify for supports in the community is wrong. And it is strictly because of the age of her husband.*

More Funding for Services

Throughout the public hearings, the request for more funding predominated. In order to better serve people with disabilities, there is a *need for better funding of community-based services and more choices for people with disabilities.* [Columbia]. In Springfield a provider summarized many of the comments made throughout the state *Bottom line is, a lot of our agencies are operating on pretty low margin and actually losing money on some programs and hoping that others get, that we get donations and such as that. Bottom line is funding. I don't know the answer to that. I really don't. I wish I did, but until we deal with that problem, I think we're going to all be frustrated trying to get whatever we get.* (Springfield).

State Agency Information: The following are representative comments received from state agencies regarding expanding or improving home and community-based services and consumer-directed care programs relative to the development of funding mechanisms:

Note: The following information from state agencies includes comments related to funding other than the Medicaid funding issues outlined in the previous section.

- Traumatic Brain Injury Program
  1. *"Policies and procedures were revised and a person centered philosophy was adopted. This change took place in July 2000 and the program manual was changed to reflect the person-centered approach. Limits on certain community-based services were removed, which created a better balance between facility based and community based services."*

- Division on Aging
  1. *"DA is required to keep the cost of all services provided to any client at or below 100% of the average annual cost of nursing facility care in Missouri. This limit is determined by the Division of Medical Services as required by CSR. (For persons who receive only basic personal care services, the dollar limit is decreased to 60k% of the average cost of nursing facility care). Current DA policy also uses this cost limit as a guideline for SSBG/GR authorizations."*
  2. *"The amount of funding available for those who need in-home services is limited and it may be difficult to meet increased demand."*
  3. *"Any time programs or services are proposed, they are dependent upon the availability of funding to support them. Additional funding would be required to clear persons from SSBG waiting lists and to provide new services or enhancements to existing programs."*

- Division of Alcohol and Drug Abuse
  1. *"The Division of Alcohol and Drug Abuse FY 2002 budget proposal includes funding requests for the expansion of community-based substance abuse treatment services for adolescents and adults. If funded, the programs will be located in areas of the state that currently have no access to such services or areas of high need, based on the division's established methodology for funding and placement of new programming."*

- Division of MRDD
  1. *"Additional funding to address waiting lists"*
     a. *The Division has 2,926 waiting for services. FY'02 Division of MRDD Budget Request (first year of a 5 year plan) is $21,636,028 plus a required Federal match of $38,711,069.*
  2. *More options for community services proposed in the coming year:*
     a. *DMH is requesting funds to serve adolescents with co-occurring (MRDD/MI) conditions ($2,388,610 GR)*
     b. *DMRDD is requesting 28 more service coordinators to better serve consumers ($1,746,054 GR)*
     c. *DMRDD is requesting additional match for Shelter Plus Care Housing fund Grant ($708,192 GR)*

- Division of Comprehensive Psychiatric Services
  1. *"According to prevalence estimates from the Missouri Comprehensive Mental Health Plan, about 45,828 Missouri adults have severe and chronic mental illness. It is estimated that 15,000 of these individuals are in need of the more intensive state funded community support services. In fiscal year 1999 only 9,253 were served in CPR while 11,387 were served in fiscal year 2000. Of the 15,000 individuals, 10,000 require housing assistance and support services in order to live in the community. The Division has requested $3,748,600 for fiscal year 2002 to expand the Community Psychiatric Rehabilitation (CPR) program and Assertive Community Treatment teams to help meet the needs of these individuals."*

  2. *"The Division provides housing supports to about 4,100 adults through our Supported Community Living (SCL) program. Although about 30% of those individuals live in normal housing and receive a housing voucher or other housing subsidy for the Division, 78% of SCL clients surveyed want to live in these independent settings. Many of these individuals could move to more independent settings with*

appropriate services and supports, housing subsidies, and the availability of safe, decent and affordable housing stock. The Division requested $2,300,00 for fiscal year 2002 to provide services and housing subsidies to help move more than 200 additional individuals form congregate living to independent living situations. The Division has also requested $1,322,598 for fiscal year 2002 to upgrade services and supports for individuals who continue to choose to reside in residential care facilities."

3. "The Division is requesting $4,411,800 in fiscal year 2002 for services and supports primarily designed to help families keep their children with severe emotional disorders at home. In addition, the Division is requesting $1,350,000 to expand the availability of treatment family homes in order to provide a home-like setting for children removed from their natural home for a period of time."

4. "Of particular relevance with regard to the Olmstead decision , is the lack of appropriate treatment alternatives for children affected by a developmental disability and severe emotional disorders. Very few appropriate alternatives exist for these children with co-occurring disorders. As a result, the Division of CPS and the Division of MRDD have collaborated to request $2,388,610 for fiscal year 2002 to jointly develop specialized services for these children and youth." (see point 2a under above MRDD section)

5. "More funding for community-based supports such as targeted case management, comprehensive psychiatric rehabilitation , new medications, supported housing, and supported employment to make these services available to all people who are eligible."

6. "More community based mental health services for people with co-existing conditions."

- Division of Vocational Rehabilitation
  1. *Eliminate the following barriers:*
     a. *Limited appropriation for Non-Medicaid Eligible program does not met the identified need*
     b. *Non-Medicaid Eligible Program is limited to Personal Care Attendant services only*
     c. *Consumer Directed Non-Medicaid Eligible Program is not available to consumers with cognitive impairments*
  3. *"Additional capacity could come from expanding the state IL waiver."*

Identification of Barriers and Recommendations by Olmstead Committees: Following are barriers and related recommendations from the Gaps and Barriers/Systems Change Sub-Committee related to Medicaid Services:

1. **Barrier:** Habilitation Centers are funded 100% up front with state dollars. Then the DMRDD bills for the 60% federal match and then the federal dollars are returned to general revenue. There is an incentive to keep all habilitation center beds full because state budget decisions are made with the expectation of reimbursement for 100% filled hab centers. Note: State centers are serving a significant number of people who are not eligible for ICF/MR due to the fact they are incarcerated at the facility. Therefore, centers need 100% funding for these individuals. **Recommendations:**
   - Institutions should be funded in the same way as any other Medicaid provider – they should bill the Medicaid Program for services provided.
   - Money should follow the individual.

2. **Barrier:** There is an underdeveloped service delivery system for people who need mental health services. Historically, money has not flowed from institutions into the community. At least in the Central Region, beds at institutions are being designated to an administrative agent to control the use of scarce beds, however, the money is not flowing through the administrative agents to pay for the beds. If the money were flowing through the Community Mental Health Centers, there would be an incentive to get people into the community. However, there is also a need to assure that there are enough state operated psychiatric inpatient beds available to meet civil and forensic involuntary hospitalization demands as well as serve as a safety net for the community.

Recommendations: Money should follow the individual and resources should be increased for community mental health services.

3. **Barrier:** The Division of Aging does not allow the use of a fiscal agent. A fiscal intermediary arrangement would allow individuals and families to direct their own services. The Division of Aging program offers Advanced Personal Care at a higher pay rate than the Division of Vocational Rehabilitation program (which only has one rate for all types of personal care) and DOA offers RN visits which is not offered in the DVR program.
   Recommendations: The DOA personal care program should implement a fiscal agent options similar to the DVR and DMRDD programs.

4. **Barrier:** Medicaid pays for personal care delivered in Residential Care Facilities, but does not pay the room and board costs of RCFs. A 100% GR cash grant is paid to the RCF. The difference between the cash grant and the cost of the RCF is taken out of the individuals SSI check (except the $25 they get to keep). RCFs are a less restrictive environment than skilled nursing facilities, but many individuals cannot afford them since Medicaid does not pay for the room and board. This keeps some individuals unnecessarily in a nursing home.
   Recommendations: Increase the spending money and Medicaid coverage in RCFs.

Recommendations:

1a. Institutions should be funded in the same way as any other Medicaid provider – they should bill the Medicaid Program for services provided.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
DMRDD administration staff will discuss a potential change in funding with the Office of Administration Budget Office.	OA	X	

1b. Money should follow the individual.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
DMRDD will implement provisions of HB1010 which allows dollars to follow persons living in a state operated habilitation center to a community living option. State habilitation center funds will be used to pay for services in the community for residents evaluated as able to live in the community and who want to live in the community.	DMRDD	X	
Recommend as a discussion for the TBI task force.	DOH		

2. Money should follow the individual and resources should be increased for community mental health services.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Division of Comprehensive Psychiatric Services will explore funding methods for facility funds to follow the individual while assuring that there are enough state operated psychiatric inpatient	DMH-CPS		X

beds available to meet civil and forensic involuntary hospitalization demands as well as serve as a safety net for the community. Also, Division of Comprehensive Psychiatric Services will request, through the budget process, increased funding for community mental health services.			

3. The DOA personal care program should implement a fiscal agent options similar to the DVR and DMRDD programs.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Jointly explore fiscal inpact	DSS-DA DSS-DMS	X	

4. Increase the spending money and Medicaid coverage in RCFs.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Jointed explore fiscal impact, cash options	DSS-DFS DSS-DMS		

Budget Items Requested for Next Year Related to Funding Mechanisms.

Needed Budget Action:

Division of Comprehensive Psychiatric Services:

Adults:

- Expand number of consumers in Community Psychiatric Rehabilitation by 3,340 - $2,732,160.
- Provide assertive community treatment teams for 600 individuals - $801,900.
- Expand the number of consumers in Community Psychiatric Rehabilitation by expanding diagnostic eligibility by 220 - $214,540.
- Funding for peer support groups, seven drop-in centers, and four warm lines - $467,500.

Children:

- Case management services for 1000 families, 45 treatment family homes; respite for 180 families; day treatment for 300 youth; recovery supports for 700 families; and family supports for 500 families - $6,496,800.

Adolescents with Co-Occuring Mental Illness and Mental Retardation/Developmental Disabilities

- Three dual diagnosis group homes; contract psychiatrist; 24 treatment family beds - $2,388,610 (This is a joint item between the Division of CPS and MRDD and is in the Directors Office of the DMH budget)

New Medications

- Availability of new medications - $5,790,870.

Federal Action:

Statute Changes:

Transportation

Background Information:

In order to live in the community, adequate transportation must be available. In rural areas, the lack of transportation can be a major challenge to community living. Even in urban areas, transportation is not convenient nor available when needed.

Summary of Related Public Comments:

Participants at the Public Hearings described issues related to problems with transportation.

If an individual with a disability is to live in the community, transportation must be available. Transportation has been a critical problem for many years, especially in rural areas. As one speaker noted *Transportation is a big barrier for people with disabilities now. If something is not put into plans, now it will be a huge barrier. Once people start moving into the community.* As a St. Louis presenter described *Transportation. Currently inadequate. And for the current needs. So there isn't any.*

Another Commission Hearing statement that reflected the lack of a state plan was *What I'm saying, though I don't think it is easy to identify because it is not like you have State transportation programs or public transportation programs. Those are different in every single community. You can't just invite MODOT say and tell us about all the public transportation you provide throughout the state. Because that's from the community up and they tap into our resources where this is a top-down system of service delivery here. There is not a state service agency delivery in terms of transportation.* (Commission Hearing 8/29/00)

Even in the city, transportation was *a major problem. We're not knocking the transportation that's available now. It is just not effective for him to live* (Kansas City). Another Kansas City consumer reported *I have to complain about our transportation. When you call in for a ride you have to call in the day before you have an appointment. If you have an appointment and you have to have another day, they won't take you. They only take you one call a day. The girls that answer the phone to get your appointments and things, they are so nasty and so hateful to you, sometimes you don't even feel like talking to them.* Transportation was an issue in St. Louis *Transportation. In St. Charles county, OATES is no longer providing transportation. They are suspending service.*

When the consumer uses a wheelchair, there is sometimes even more difficulty in obtaining transportation *folks who are wheelchair users in their homes that do not have access to wheelchair accessible*

transportation or they do not own a wheelchair accessible vehicle or they don't know that they can acquire the equipment to adapt their vehicles to be wheelchair accessible (Kansas City).

State Agency Information: The following are representative comments received from state agencies regarding expanding or improving home and community-based services and consumer-directed care programs relative to the development of funding mechanisms:

- Comprehensive Psychiatric Services
  Lack of public transportation, particularly in non-urban areas of the state, is always a problem for people with disabilities. This is particularly true for persons with serious mental illness who many times have very limited incomes and do not have their own transportation.

- Aging
  Transportation needs beyond those currently available through public systems. The Non-Emergency Medicaid Transportation (NEMT) program, OATS, and others may not meet the particular needs of the younger disabled population.

- Division of MR/DD
  Transportation is an issue. Consider issuing vouchers or stipends for transportation services.

Identification of Barriers and Recommendations from the Olmstead Committees:

Following are barriers and related recommendations from the Olmstead committees related to transportation:

Barrier: There is an inadequate accessible transportation system in urban and rural areas. Without transportation, people are isolated and are not fully integrated into the community.

Recommendations:

- Immediately reactivate, improve and expand the Coordinating Council on Special Transportation established in Missouri statute.
- The state should look at giving people stipends or vouchers to purchase their own transportation.

Timelines and Responsible Parties to Implement Recommendations: The following table summarizes recommendations, identifies agency(ies) responsible for planning and initiating activities to realize each recommendation, and identifies the calendar year in which the results will be achieved:

Recommendations:

1a. Immediately reactivate, improve and expand the Coordinating Council on Special Transportation established in Missouri statutes.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Division of Comprehensive Psychiatric Services will participate in the reactivated Coordinating Council on Special Transportation as requested	DMH-CPS		
If appropriate, DMRDD staff will participate on the Coordinating Council on Special Transportation.	DMRDD		X

1b. The state should look at giving people stipends or vouchers to purchase their own transportation.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

Budget Items Requested for Next Year Related to Transportation.

Needed Budget Action:

Federal Action:

Statute Changes:

Employment

Background Information:

According to national statistics, persons with disabilities are unemployed or underemployed. Employment is a sector where progress has been slow in assuring that persons with disabilities have adequate paying jobs with benefits.

Summary of Related Public Comments: Participants at the Public Hearing described issues related to their personal challenges in obtaining employment and in assisting others obtain work.

I would love to go to work tomorrow and I could go to work tomorrow if it wasn't for the fact of my medical condition and needing Medicaid. Until we can take hold and receive economic power to be able to have control over our own lives from an economic standpoint... things are not going to change (Springfield).

Currently, there are many supports for sheltered employment. There are few incentives for people in the community who hire persons with disabilities. *This is another case where there are state subsidies that go to*

employers who provide segregated employment like sheltered workshops but there are no state subsidies that I'm aware of that go directly to employers who are willing to hire people with developmental disabilities (Columbia). A Kansas City speaker described the lack of *employment or supports for living a meaningful day* (Kansas City).

The issue of supported employment arose in Springfield also. *Where does supported employment come into this? Is that involved in any of this?* Another speaker further elaborated on this S*upported employment situations in most cases are preferable. But you need a lot of supports of various kinds for people with disabilities to move into supported employment situations sometimes. One of the biggest barriers is in the State law. State law which governs Senate Bill 40 Boards. We are mandated and I mean Senate Bill 40 Boards to fund sheltered workshops. I'm not here to say that there's not a place for sheltered workshops. Perhaps there is, but I think a good many of us feel that the State law is much too restrictive. I think a good many Senate Bill 40 Boards could use some of this funding for more supported employment situations were we not mandated to use a lot of it for sheltered workshops* (Springfield).

Support employment was also advocated in St. Louis *One gentleman with autism was kicked out of a workshop because of behavior challenges he faces. With the help of a supportive employment program that I work with, he held the same part time job for nine years, until the company closed.*

We're very concerned that while pay levels have fallen so far behind in this time of virtual full employment, that we are truly facing a crisis. (Commission Hearings 11/13/00)

Identification of Barriers and Recommendations from the Olmstead Committees:

Following are barriers and related recommendations from the Olmstead Committees related to employment.

Barrier: There are not adequate employment options to give people with disabilities choices to work in a community-integrated setting either through competitive or supported employment. There are insufficient funds for community-integrated employment programs.

Recommendations:

- Look for ways to make it easier for people with disabilities to secure and maintain employment.
- Increase funds for supported employment.
- Look for ways to continue Medicaid when the person with disabilities becomes employed.

Timelines and Responsible Parties to Implement Recommendations: The following table summarizes recommendations, identifies agency(ies) responsible for planning and initiating activities to realize each recommendation, and identifies the calendar year in which the results will be achieved:

Recommendations:

1a. Look for ways to make it easier for people with disabilities to secure and maintain employment.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Division of Comprehensive Psychiatric Services will request funding in the FY02 budget to fund 24 new case manager assistant positions in the Comprehensive Psychiatric Rehabilitation Program to be filled by consumers appropriately trained to provide direct services to other consumers. Also, Division is requesting funding for peer support grants, 7 drop0in centers, and 4 warm lines to be operated by and employee consumers.	DMH-CPS		X

DMRDD will investigate the feasibility of implementing a pilot community employment support service that pays the provider when specific outcomes (milestones) are achieved.	DMRDD	X	
DMRDD will work with Division of Medical Services and other interested agencies and representatives on the TWWIIA Medicaid Infrastructure Grant to explore a Medicaid Buy-In Option and to explore adding flexibility to the state plan Medicaid service, personal care.	DMRDD	X	

1b. Increase funds for supported employment.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002

1c. Look for ways to continue Medicaid when the person with disabilities becomes employed.

Activities	Responsible Agency(ies)	Year Achieved 2001	2002
Budget item submitted for ticket to work and Work Incentives Act Medicaid eligibility groups	DSS-DMS DSS-DFS	X	
DMRDD will work with Division of Medical Services and other interested agencies and representatives on the TWWIIA Medicaid Infrastructure Grant to explore a Medicaid Buy-In Option and to explore adding flexibility to the state plan Medicaid service, personal care.	DMRDD	X	

Budget Items Requested for Next Year Related to Employment.

Needed Budget Action:

- Budget item submitted for Ticket to Work and Work Incentives Act Medicaid eligibility groups.
- Division of Comprehensive Psychiatric Services FY 02 budget item – Funding for 24 new case manager assistants - $601,490 and funding for peer support grants, 7 drop;-in centers, and 4 warm lines - $467,500.

Federal Action:

- Waiver cost neutrality is a Federal issue.

Statute Changes: